Participation in meaningful occupation: How do young adults living with cerebral palsy experience the quality of their participation?

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"Research Assignment presented in partial fulfilment of the requirements for the degree of Master of Occupational Therapy at the Stellenbosch University"

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March 2013

Declaration

By submitting this research assignment, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualifications.

Date: December 2012

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ENGLISH SUMMARY

Participation in meaningful occupations is what defines us as human beings and is an important indicator of health and well-being. It is the way we experience the world around us and is closely linked to quality of life. As an occupational therapist at a school for learners with special educational needs, the researcher was interested in how young adults with a diagnosis of Cerebral Palsy (CP) who attended this school, experience their participation or the lack thereof in occupations and if it contributes to meaning and fulfilment in their lives? She established through informal conversation with some of these young adults or their parents, that they experience unemployment, unhappiness and poor integration within the community. The aim of this study was therefore to describe how young adults living with CP in economically disadvantaged communities within the Western Cape, experience the quality of their participation in meaningful occupations.

A qualitative phenomenological study design was used, enabling the researcher to explore the value and meaning participants attach to different occupations, the participants perceptions of their experience and the factors impacting on their participation. The study population was young adults between the ages of 18-28 years with a diagnosis of CP, who attended the previously mentioned school and who exited school over the duration of the past nine years. The researcher used purposive maximum variation sampling, to ensure variation in terms of diagnosis, living arrangements, employment and marital status. Data collection took the form of ten face-to-face semi-structured individual interviews and inductive content analysis was utilized to analyse data. The following four themes emerged from the data: overcoming challenges; having equal opportunities; barriers holding me back and the future is mine to shape. These young adults participated in a variety of meaningful occupations and have learned to utilize various strategies to overcome the difficulties they faced in this process. The following factors influenced their participation positively: having meaningful relationships; accepting their disability and nurturing a positive attitude; being proud of their achievements; positive work experiences and involvement in the community. Factors contributing to these young adults not experiencing meaningful participation were the following: their perception of themselves and also how they perceived being treated by others; non-acceptance of their physical circumstances and disability; incompetence and poor self-confidence; termination of previously meaningful occupations; challenges with interpersonal relationships and unsatisfactory work experiences. The need to be as independent as possible was of utmost importance to all these young adults, as it was an indicator of being in control of their own lives. Given the above information, the researcher recommends a transition preparation program for senior phase learners that will include sessions on work habits, social skills, transportation, self-employment and integration into the community to be implemented at the school. Supported employment options should be explored as well to ensure maximum employment among these learners exiting school. A follow-up system should be established to evaluate the effectiveness of the above-mentioned program.

AFRIKAANSE OPSOMMING

Deelname in betekenisvolle aktiwiteite is uniek aan die mens en is ook ‘n belangrike aanduiding van gesondheid en welstand. Ons ervaar die wêreld rondom ons deur betekenisvolle deelname, was nou verbind word kwaliteit van lewe. Tydens haar werk as ‘n arbeidsterpeut by ‘n skool vir leerders met spesiale onderrig behoeftes, het die navorser begin belangstel in hoe jongmense met ‘n diagnose van serebraalgestremdheid (wat oudleerders is) hulle deelname aan aktiwiteite of die gebrek daaraan ervaar en of dit bydra tot betekenisvolheid en vervulling in hulle lewens. Sy het deur informele gesprekke met van hierdie jongmense of hul ouers vasgestel dat hulle ervaring ongelukkig, werkloos and swak geïntegreed in hulle gemeenskap is. Die doel van hierdie studie was dus om te beskryf hoe jongmense met ‘n diagnose van serebraalgestremdheid wat in ekonomies benadeelde gemeenskappe binne the Weskaapse Provinsie woon, die kwaliteit van hul deelname aan betekenisvolle aktiwiteite ervaar. Die navorser het ‘n kwalitatiewe fenomenologiese studie ontwerp gebruik sodat sy die volgende aspekte kon verken: die waarde en betekenis wat die studie deelnemers aan spesifieke aktiwiteite heg; hulle persepsie van hulle ervaringe, asook die faktore wat deelname beïnvloed. Die studiepopulasie was jongmense tussen die ouderdomme van 18-28 jaar oud met ‘n diagnose van serebraalgestremdheid, wat die bogenoemde skool bygewoon en verlaat het in die afgelope nege jaar. Die navorser het ‘n doelgerigte maksimum variasie steekproef gebruik, om sodoende variasie in terme van diagnose, verblyf, werk en getroude status te verseker. Data was ingesamel deur middel van tien semi-gestruktureerde individuele onderhoude. Induktiewe inhoud-analise was gebruik om die data te ontleed en die volgende vier temas het na vore gekom naamlik: om uitdagings te oorkom; om gelyke geleenthede te hê; hindernisse wat my terughou en die toekoms is myne om te vorm. Hierdie jongmense neem deel aan ’n groot verskeidenheid aktiwiteite en het deur ondervinding verskeie strategieë aangeleer om die probleme wat hulle ervaar het te oorkom. Die volgende faktore het hulle deelname positief beïnvloed: betekenisvolle interpersoonlike verhoudings; aanvaarding van hulle gestremdheid en koestering van ‘n positiewe houding; trots op hulle prestasies; positiewe werkservaringe en betrokkenheid in hulle gemeenskap. Die faktore wat bygedrae het tot swak deelname aan aktiwiteite was die volgende: hul self-persepsie, asook hul persepsie van hoe ander hulle behandel; nie-aanvaarding van hulle gestremdheid en fisiese omstandighede; swak selfvertroue en gevoelens van onbevoegdheid; die staking van vorige betekenisvolle aktiwiteite; uitdagings in hulle verhoudings en onbevredigende werkservaringe. Hul onafhanklikheid is vir hierdie jongmense van uiterste belang, want dit is ‘n aanduiding dat hulle in beheer is van hulle eie lewens. Na aanleiding van bogenoemde informasie, maak die narvorser die volgende aanbeveling: Om ‘n voorbereidings program vir senior fase leerders te begin, wat sessies van werksgewoontes, sosiale vaardighede, transport, self-indiensneming en integrasie in die gemeenskap insluit. Die moontlikheid van ondersteunde indiensneming moet ook verken word, om maksimale indiensneming onder hierdie jongmense te verseker. ‘n Opvolg sisteem moet ook in plek gestel word om die doeltreffendheid van bogenoemde program te bepaal.

Acknowledgements

I would like to thank the following people who played a major role in me completing this Master Degree:

- My parents for giving me the opportunity to study occupational therapy 22 years ago, for always believing in me, even when I did not and for encouraging me to “do the best you can”.
- My loving husband for supporting me emotionally, physically and financially throughout this journey, by offering cups of tea, a shoulder to cry on, sacrificing his time to assist me and doing all the extra chores at home, while I sat in front of my computer. For always loving and understanding me, even when I was so miserable to be around with.
- My two study leaders who have gone above and beyond their duties to see me through this process, always being there with open ears and minds for my ideas and encouraging me to go on and finish what I started.

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CHAPTER 1: INTRODUCTION

"For if we do not have ordinary and familiar occupations in our daily lives and if these occupations do not have personal significance to us, then who are we and what is the purpose of life?"[1]

1.1 Rationale and problem statement

With the above statement Hasselkus[1] summarizes the importance of participation in meaningful occupations for all human beings. Polatajko, Backman, Baptiste, Davis, Eftekhar, Harvey, Jarman, Krupa, Lin, Pentland, Rudman, Shaw, Amoroso, Connor-Schisler[2] stress the fact that humans are born as occupational beings. They also argue that the significant link between meaning and occupation is deeply intertwined in our believes, our identities and how we portray ourselves to the world through occupation.[2] Looking back into history, going as far back as the sixteenth century, Jefferson, as quoted in Polatajko, Davis, Stewart, Cantin, Amoroso, Purdie, Zimmerman[3] already spoke about the importance of occupation in gaining happiness, when he stated that being happy is not dependent on our life situation, but is always the consequence of "good conscience, good health, occupation and freedom in all just pursuits."

More recently the World Health Organization (WHO) has, since the development of the International Classification of Functioning, Disability and Health (ICF), placed a lot of emphasis on participation as an important outcome of health and well-being.[4] Law[5] states that participation in everyday occupations defines us as humans and helps us learn new skills, connect with others and find meaning in life. It has a positive effect on one's quality of life, but the lack thereof results in poor health and well-being.[5] After developing four propositions about the nature of meaningfulness in occupational therapy and occupational science, Ikiugu[6] came to the same realization that people who participate in meaningful occupations experience feelings of well-being, because their psychological needs are being met.

How can we define meaningful participation in occupations of everyday life? By having an understanding of what "occupations" are. Occupations are defined as the "activities people engage in throughout their daily lives to fulfil their time and find meaning in life."[7] Occupational therapists' core focus is to have an understanding of occupation and their practice is based on the belief that health and well-being of persons with disabilities can be improved by using occupation as means.[1,8] Hasselkus[9] encourages occupational therapists to obtain greater insight into the meaning and significance their clients attach to everyday occupations. The researcher therefore wondered how young adults living with cerebral palsy (CP) experience their participation or the lack thereof in occupations and if these occupations are meaningful, contributing to fulfilment in their lives? From an international perspective, Law[5] looked at various studies done by Blake, 1995;

Dunn, 1990; Idler & Kasl, 1997; Pentlend, Harvey, Smith and Walker, 1999 and concludes that disability has a significant impact on participation. It leads to less diverse and active participation, with less involvement in social relationships.[5]

Nationally, Konig[10] (July 2009), a physiotherapist who works extensively with children and adults with CP in South Arica, summarized it well in one of her lectures, when she made the following statement:

> *Most children / adolescents and adults with disabilities want what all people want in life – happiness, independence, being believed in, fulfilling relationships and meaningful occupations and being accepted by others. They will however have difficulty in attaining these goals, due to prejudice, environmental barriers, socio-economic circumstances and lack of skill.*

The researcher supported the abovementioned view as from experience, whilst working as an occupational therapist at a school for learners with special educational needs (LSEN), as she often had the opportunity to engage with ex-learners diagnosed with CP and found that unemployment, unhappiness and living an isolated life in their community are quite common amongst them. The researcher realized that all people has the same need for happiness, fulfilment and living a meaningful life, but learned through informal conversations with some of these ex-learners and their parents, that this is often contrary to what persons with disabilities (PWD) experience.

This is despite the fact that in our new dispensation, there has been a lot of focus on the rights of all human beings including PWD.[11] When the Integrated National Disability Statement was introduced in South Africa in 1997, Deputy President Thabo Mbeki stated that people with disabilities can play a significant role in the development of society, and should not be viewed as "objects of pity."[12] Policies developed by the South African democratic government since their re-integration into the international community in 1994, are seen as some of the most progressive in the world.[13] We are one of a few countries whose constitution includes disability issues.[13] Unfortunately, South African specific research about the impact of these policies is not widely published, as was determined by the Office of the Status of Disabled People (OSDP).[11] The OSDP was established in 1996, with the mandate to coordinate and mainstream disability policies.[11] One of their outcomes was the development of the Integrated National Disability Strategy White Paper (INDS).[11] The OSDP commissioned a study about the effectiveness and efficiency of disability policy implementation and found that only a few policies were implemented effectively namely: the Employment Equity Act (EEA), Skills Development Act (SDA), Promotion of Equality and Prevention of Unfair Discrimination Bill and the Code of Good Practice on Employment of PWD.[11] Several authors found that these legislation and policies had no significant impact on reducing inequalities in the lives of PWD.[11,14,15]

The researcher therefore became interested in learning more about the quality of life of learners with a diagnosis of CP, once they have left school. She found that studies about the experience and perceptions of young adults with CP on the quality of their participation in meaningful occupations are scares in the literature. Authors in South Africa, Germany, Sweden and Stockholm similarly find that limited research has been done on participation restrictions, subjective and occupational well-being in adults with CP.[16-19] Reed, Hocking and Smythe[20] also discover that minimal research has been done in New Zealand on the meaning of specific occupations or aspects of occupation.

The researcher realized that the voice of these young adults has not been heard before. Therefore there was a need to know how young adults living with CP experience the quality of their occupational participation. Thus the question remains: How do young adults with CP experience the quality of their participation in meaningful occupations?

1.2 Purpose of the study

The purpose of this study was to gain better insight into the experiences of young adults living with CP, about the quality of their participation in meaningful occupations.

1.3 Aim of the study

The aim of this study was to describe how young adults living with CP experience the quality of their participation in meaningful occupations.

1.4 Objectives:

To explore the value and meaning participants attach to different occupations.

To explore the participants' experience and the factors that has an impact on their participation in occupations.

To gain information on their relationships and the impact it has on their occupational participation.

1.5 Delineation of study

The study participants were young adults between the ages of 18-28, with a diagnosis of CP, who attended a LSEN school catering for learners diagnosed with CP and learners experiencing barriers to learning, in the Cape Metro-pole within the Western Cape. The school follows a mainstream curriculum and the medium of instruction is in Afrikaans and English.

1.6 Outline of the research assignment

In chapter two the researcher will summarize the most recent and relevant literature relating to the phenomenon being studied. Chapter three will cover the methodology, including the study design, sampling, data collection, data analysis and ethical considerations. Chapters four and five will cover the results and discussion of the findings respectively. The conclusion and recommendations will be discussed in chapter six.

The researcher will subsequently discuss the literature which was reviewed, in order to gain a better understanding of the phenomenon being studied.

CHAPTER 2: LITERATURE REVIEW

The researcher searched for South African context studies, as well as studies done in other countries that investigated meaningful participation in occupations in the lives of young adults with a diagnosis of CP. In this chapter the researcher attempted to critically analyse literature on issues pertaining to CP; young adulthood; meaningful participation; what occupation entails; the meaning of quality of life; spirituality; work and self-care; leisure and community involvement, as well as romantic relationships.

2.1 Cerebral palsy

Cerebral palsy is a well known neurodevelopmental condition with its onset in early childhood and persisting through life.[21] It can either be congenital or acquired. Congenital, caused by e.g. lack of oxygen, complex pregnancies, preterm births, low birth weight, trauma to the developing foetus, or it can be acquired as the result of brain infection, bacterial meningitis, accidents or head injuries to the developing brain of a young child.[22]

2.1.1 Definition

Cerebral Palsy describes “a group of permanent disorders of movement and posture, causing activity limitation that are attributed to non-progressive disturbances occurring in the developing foetal or infant brain.”[21] The motor disorders of cerebral palsy are often accompanied by disturbances of sensation; perception; cognition; communication; behaviour; epilepsy and by secondary musculoskeletal problems.[21] A considerable proportion of people diagnosed with CP have some kind of cognitive impairment, with increased probability when epilepsy is present.[23]

2.1.2 Classification

Classification of CP can be based on the following:[22]

- *Severity level* with mild indicating no limitation in performance of daily activities, moderate indicating a need for adaptive equipment to accomplish activities of daily living and severe meaning non-ambulance and significant difficulties in performance of daily activities.
- *Topographical distribution* is a description of the body parts affected e.g. hemiplegia; diplegia; triplegia and quadriplegia.
- *Motor function* including spastic and non-spastic. Spasticity refers to increased muscle tone and accounts for 70-80% of cases, e.g. spastic diplegia and quadriplegia. Non-spastic CP is characterized by decreased or fluctuating muscle tone and involuntary movement, e.g. ataxia; dystonia and athetosis.

- *Gross Motor Function Classification System* (GMFCS) is a universal system assisting professionals in determining the intervention required, in terms of surgeries, treatments, therapies and assisted technology, in order to help a child function optimally.

Rosenbaum, Paneth, Leviton, Goldstein and Bax[21] find that classifying persons with CP into distinct clinical groups is useful but not straightforward. They propose looking at four components of classification: motor abnormalities, accompanying impairments, anatomical and neuro-imaging findings, causation and timing.[21] This is in line with the recent publication of the ICF, which is a universal classification system developed by the WHO in 2001 and focuses on the components of health, rather than the consequences of disease.[4] It also emphasizes the importance of environment, which includes the family and recognizes the importance of personal choices, interests, as well as self-defined goals.[4]

2.1.3 Prevalence

According to the CP Association of South Africa, 1,600 babies are diagnosed with CP in South Africa each year.[24] Census 2001 indicated that out of the 5% of the South African population with a disability, 29.6% has a physical disability.[25] The researcher could not find literature on the prevalence or incidence of CP within the Western Cape.

2.1.4 Functional problems

Rosenbaum et al.[21] refers to the following functional problems in their report, on the definition and classification of CP:

- Motor problems cause difficulties with activities like walking, feeding, swallowing, coordinated eye movements and speech articulation.[21]
- Expressive and/or receptive communication and/or social skills may be affected.[21]
- Psychiatric or behavioural problems including autistic spectrum disorders, ADHD, sleep disturbances, mood and anxiety disorders.[21]

Roebroeck, Jahnsen, Carona, Kent, and Chamberlain[26] reviewed several studies about participation restrictions and conclude that a considerable number of young adults with CP experience restriction in participation. Before we can understand the young adult living with CP, we need to know more about the typical development of young adults.

2.2 Early Adulthood

Entering adulthood is a major change in life and is characterized by the following developmental tasks: exploring intimate relationships, including marriage; childbearing; work and developing a lifestyle.[27] It is during this developmental stage that individuals experience the "demands of many of their roles" and it can become a major cause for stress.[28] Being involve in various roles plays an important part in the developmental of personality and allowing adults to serve as instruments of "socialization for the younger generation."[28] The developmental tasks will subsequently be described in terms of marriage, child bearing, work and lifestyle.

2.2.1 Exploring intimate relationships

Most young adults hope to get involve in either a dating or friendship relationship, which will eventually ends in marriage.[27] For most adults the main indicator of happiness in life is having a fulfilling marriage,[28] although Michelsen, Uldall, Hansen and Madsen[29] found that in today's time many couples are unmarried in Denmark and many other countries.

2.2.2 Childbearing

The decision to have children or not is often decided in the first few years of marriage.[28] Having children provide love and companionship to adults and prevent them from being lonely.[28] The experience of childbearing enhances the individual's sense of being and their believe that decisions made as an adult actually matter.[28] Being a parent is an exceptional experience of adulthood and a chance to learn more about "nurturance, playfulness and authoritativeness."[28]

2.2.3 Work

Early adulthood is seen as the experimental and training phase of work.[28] Many adults experience a sense of worth and social status through work.[27] Our financial independence, activities we participate in, relationships, satisfaction with life, as well as difficulties and struggles are in large part determine by our work.[27] Newman and Newman[27] identify four central components of the work situation and suggest that young adults assess the match between their personal characteristics and these components, being: technical skills, authority relations, demands and hazards, as well as interpersonal relationships with co-workers.

2.2.4 Developing a lifestyle

Lifestyle includes the rhythm of occupation, balancing work and leisure, "establishing a circle of friends" and choosing activities reflecting one's values.[28] The following factors are most important

in the creation of a lifestyle in early adulthood: marriage, marriage partner, children and work.[28] These factors lead to a relatively permanent way of living.[28]

Roebroeck et al.[26] make reference to the fact that transitioning into adulthood is difficult for all people, but more so for the young person with disabilities, including CP. Murphy and Bliss[30] likewise experience that transitioning from adolescence into adulthood can be very challenging for people with a diagnosis of CP. According to Cogner, Savage and Smith[31], the extent to which they conquer the obstacles entering into adulthood depends on the severity of their impairment, how they have been taught to deal with their disability and how PWD are regarded by and accommodated within society. Before discussing the outcome of studies in the literature regarding this, a more comprehensive understanding of meaningful participation is necessary.

2.3 Meaningful participation

It is necessary for us to understand meaning, in order to explain the true nature of occupation.[20] Meaning is created in our minds and it helps us make sense of our experiences.[2] We communicate our sense of meaning and purpose to the world through or words, actions and attitude.[2] In his article about "Activity and Happiness", Csikszentmihalyi[32] argues that in order to attain a fully meaningful life one has to find occupations that are challenging, but within your range of abilities. Reid[33] again, states that meaningful occupations are a good fit between one's abilities and interests, while Håkansson, Dahlin-Ivanoff and Sonn's[34] participants felt that an occupation is personally meaningful if it's challenging and something that you are skilled at or improving on. Reed et al.[20] did a hermeneutic phenomenological study in New Zealand with 12 adults who had experienced a disruption to their occupations. They found that the meaning of occupation is formed by the "dynamic interplay" between the three themes that emerged from the study: the call ("the meaning of occupation is at the heart of who we are"), being-with ("occupation act as the vehicle for the coming together and in the coming together the meaning of occupation shows itself") and possibilities ("it is through occupation that people become aware of the opportunities that open up or close down for them").[20] This is in line with what Husselkus[1] wrote in her book: "Occupation is a powerful source of meaning in our lives; meaning arises from occupation and occupation arises from meaning."

2.4 Occupation

Occupation is seen as an tremendously multifaceted phenomenon and because research has been very limited until recently, many questions about its relationship to health and well-being remain unanswered.[7] The following domains of occupations traditionally used by occupational therapists in our present day include work, self-care, play, leisure, spirituality and sleep.[7] Although

these general domains are familiar across all cultures, the definition and specific tasks which comprise each domain differs across individuals. Occupations also have the following dimensions: performance; contextual; temporal; psychological; social; symbolic and spiritual.[7] In 1993 Wilcock[35] spoke about occupation as a central aspect of the human experience and identified the three major functions of occupation as:

- providing for immediate bodily needs of sustenance, self-care and shelter,
- developing skills, social structures and technology aimed at superiority over predators and the environment,
- exercising and developing personal capacities to enable the organism to be maintained and to flourish.

All the above functions are interplay between the person, their environment and their occupations. These cannot be separated from each other and each component or factor brings with it its own unique characteristics. Both the Person-Environment-Occupation[36] (PEO) and ICF[4] models emphasize the importance of the personal and environmental factors. According to the PEO model the dynamic relationships between people, their occupations or roles and the environment they live, work or play in, result in occupational performance.[36]

Hasselkus[1] proposes that occupation is the "vehicle by which we can experience our worlds." She discusses the idea that we balance our lives by making choices, conscious and unconscious, about what occupations we will continue with, which ones we will stop engaging in and possible new ventures we will take on.[1] Polatajko et al.[3] argue that there is a difference between having occupations and performing them. Important to note, is the fact that we often engage in occupation without performing it.[3] However, the performance or doing part of occupation has received the most attention in the history of occupational therapy.[7] According to Hasselkus[1] the different definitions of occupation focus mostly on the doing part. She commends Wilcock for looking at occupation differently, by describing it as the fusion of "doing, being and becoming".[1] Wilcock[37] describes "doing" as the part of occupation that implements, maintains and develops physical and mental abilities. She further suggests that the notion of "being" is about being true to yourself, taking time to think, reflect and just exist.[37] "Becoming" is then seen as the idea of potential, growth, change and self actualization.[37] "Being" and "becoming" can be seen as the meaning aspects of occupation.[1]

To experience rewarding engagement in meaningful occupations or a lack therefore, greatly affects all people regardless of ability.[38] According to Christiansen and Townsend (2004) as cited in Renwick[38], "meaningful occupational engagement has been positively associated with quality of

life." This brings us to the questions that were asked by Goldstein and Bax:[39] What is quality of life, who determines its present status and that there has been a change?

2.5 Quality of life

The concept of quality of life (QoL) is now widely recognized not just within the scientific and disability fields, but also in the political and social policy domains.[40] Quality of life is the individual's "perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[41] The above definition of QoL by the WHO[42] emphasizes the fact that it is subjective, multi-dimensional and inclusive of positive, as well as negative aspects of life. Renwick[38] speaks about having good QoL when we live an excellent life, filled with enjoyable, meaningful and thoroughly felt experiences. The idea of life satisfaction includes factors like job satisfaction, leisure time and other areas of participation, whereas well-being or happiness are influenced by subjective attitudes, self-esteem, personal values and beliefs.[18] According to Colver[43] one cannot measure QoL directly, as it is "captured by calculating from a group of questions the value of an underlying latent variable." An international QoL assessment was developed in 1995 by the WHO.[42] It contains 235 core questions addressing 29 facets of QoL, which is organized into the following domains: physical; psychological; level of independence; social relationships; environment; spirituality; religion and personal beliefs.[42]

Although a QoL questionnaire for children with CP[44] has been developed, the researcher finds that there are currently no QoL assessments specifically designed for young adults with CP. Rosenbaum's[45] view about QoL assessments differs, as he suggests that condition-specific assessment instruments allow for better understanding of the individual disorders, but gathering of data and comparing across different conditions are complicated.[45] There seem to be many health-related QoL measures in the literature, but according to Rosenbaum[45] an alternative way to assess QoL, is to investigate people's "subjective valuations of their well-being."

Hergenröder and Blank[18] found that limited research has been done on the subjective well-being in regards to life satisfaction in adults with CP. They conducted a pilot study with a randomized sample of 50 adults with spastic CP, looking at subjective well-being and life satisfaction, using psychosocial and sociomedical measures.[18] Andren and Grimby[17] looked at dependence in daily activities and life satisfaction in adults with CP or Spina Bifida, living in Sweden. The results showed that young adults with CP or Spina Bifida have similar levels of life satisfaction as the average population.[20] Roebroeck et al.[26] found the opposite in that adults with CP view their overall quality of life to be lower than the reference group of the same age. Rimmerman and Crossman[46] looked at the quality of life of 128 single adults with severe disabilities who participated in an

extended employment program in Northern Israel, using a quantitative study design. Structured interviews were conducted and one of the outcomes of special interest to me is the fact that those who had the perception that their disability is milder and did not participate in non-employment activities at their work place, experienced greater quality of life.[46] Rozario (1992,1994), as quoted in Townsend[47] states that occupational therapists have identified spirituality as an essential aspect of QoL.

2.6 Spirituality

Specht, King, Willoughby, Brown and Smith[48] explored spirituality as a coping mechanism in the lives of adults with congenital disabilities. They conclude that spirituality influences the participants' view of their disability, by giving them a belief about the purpose of life.[48] As this study is about meaningful participation in occupations the researcher found the following quote from Howard and Howard[49] very appropriate to demonstrate the link between spiritually and occupation: "Occupation can be seen as fundamentally spiritual and spirituality as imbedded in occupation." Fulgham (1995) as cited in Christiansen[50] believes that some of the following activities can nurture the soul by providing opportunities to create meaning: reading; expressive art; visiting museums, historical places and galleries; music; walking in nature; meditation; gardening and letter writing. Having a clearer understanding of meaningful participation in occupations, QoL and spirituality, we can move on to discuss the results of various studies in the literature regarding work, self-care, leisure and community involvement, as well as romantic relationships.

2.7 Work and Self-care

"Participation in work is an important 'life activity', offering income, social relationships, social status, daily rhythms and often meaning in life."[51] In South Africa the 1998 CASE survey of disability found an overall employment rate of 12 percent for people with disabilities.[52] In a 2008 report by the Department of Labour on the Employment Equity Act (EEA), it states that people with disabilities do not apply for jobs or are not employed when they do apply.[53] The reason for this being, jobs advertised for people with disabilities only, are perceived by the disabled person as not important.[53] Reasonable accommodation is defined in the EEA as "any modification or adjustment to a job or to the working environment that will enable a person from a designated group to have access to or participate or advance in employment."[54] Rheeder[55] advises designated employers to begin to reasonably accommodate disabled employees, as their employment is of high priority to the Department of Labour. Within the South African context, it also appears that a person who acquired impairments or became disabled at a younger age, "are less likely to be employed."[52]

Similarly, adolescents and young adults with disabilities living in Canada still experience discrimination and encounter various barriers when seeking paid employment.[56] On the other hand it seems as if employment opportunities for young adults with CP living in the USA have increased due to advances in technology, improved home support services, legal mandates, educational and environmental access.[30] Lindstrom, Doren and Miesch[57] also experienced that when young adults have a solid foundation of transition services, they can become financially independent. Michelsen et al.[29] found in their quantitative study that young adults with CP living in Denmark, were "poorly integrated socially in education, employment and sport activities," although they demonstrated a high level of independence in performing activities.[29] Some of the possible reasons for this were identified as cognitive or perceptual deficits and physical fatigue.[29] Michelsen et al.[29] argue that the above problems might explain why even the "most optimally functioning adults" struggle with integration in cohabitation, children and the work place.

Van der Dussen, Nieuwstraten and Stam's[58] study in Den Haag looked at the functional level of young adults with CP, using a structured questionnaire including the Barthel Index. Their outcomes were similar to those of Michelsen et al.[29] in that participants were very independent in activities like self-care, mobility and communication, but continued to be poorly integrated socially in terms of education, paid employment and sports activities.[58] Donkervoort, Roebroeck, Wiegerink, Van der Heijden-Maessen, Stam and The Transition Research Group South West Netherlands's[59] quantitative study demonstrates that a significant number of adolescents and young adults with CP (without severe learning disabilities) experience restricted participation in areas of mobility, self-care, nutrition, employment, taking responsibility, community involvement and leisure activities.

2.8 Leisure and Community involvement

Participation in leisure activities is closely linked to the following factors: the individual's functional status; being employed; living arrangements; having children and socio-economic status.[60] In their cross-sectional study Van Naarden Braun, Yeargin-Allsopp and Lollar[60] found that both young adults with and without impairment are participating in a rich diversity of leisure activities. Involvement in peer group activities which create opportunities for dating, seems important for young adults with CP to develop romantic relationships and sexual activity.[61]

2.9 Romantic Relationships

Little is known about the development of romantic relationships among young adults with CP.[61] Wiegerink, Roebroeck, Donkervoort, Stam and Cohen-Kettenis[62] conducted a literature review to investigate possible barriers to successful social and sexual relationships in adolescents and

young adults with CP (with normal intelligence) in 2005. They searched two databases for the period 1990-2003. From the 14 papers that were reviewed it emerged that adolescents and young adults with CP do not develop as well as their typical developing peers in social relationships. It is apparent that their "dating is often delayed and less frequent."[62] In 2009 Wiegerink, Roebroeck, Van der Slot, Stam, Cohen-Kettenis and The Transition Research Group South West Netherlands[61] came to the same conclusion in their study about the importance of peers and dating in the development of romantic relationships and sexual activity of young adults with CP: Young adults with CP have significantly less experience of romantic relationships and sexual activities than typically developing peers, because of less participation in peer group activities and dating.

2.10 Summary

In this chapter the most recent and relevant literature relating to key concepts of this research study has been reviewed, including, young adulthood, CP, meaningful participation, occupation, QoL, spirituality, work, self-care, leisure, community involvement and romantic relationships. In chapter three the researcher will discuss the methodology applied in this study.

CHAPTER 3: RESEARCH METHODOLOGY

This chapter entails a detailed discussion about the qualitative methodology, to answer the question which aimed to describe how young adults living with CP, experience the quality of their participation in meaningful occupations. The discussion includes the study design, target population, sampling methods, data collection, data management, rigor and trustworthiness, as well as ethical considerations.

3.1 Introduction

The researcher found that the phenomenon of human occupation and how it relates to life satisfaction and well-being is quite complex, therefore a qualitative phenomenological study design was used. With qualitative methodology the researcher seeks to understand the intricacy of human beings.[63] Occupational therapy includes the study of human occupation and how it relates to one's own health, contentment and the "sense of well-being."[64] Therefore qualitative methodology enabled the researcher to explore the different occupations, their value and meaning, as well as the participants' perceptions of their experiences and the impact of relationships on participation.

3.2 Study Design

The chosen study design and the research setting will be discussed.

3.2.1 Phenomenological study design

A phenomenological design was chosen, as it tries to move beyond the exterior to understand the underlying vital meaning of the individual's experience.[65] Lala and Kinsella[66] found that the use of phenomenological methodology contributes to notice and create "unique contributions" and important "insights" into the study of human occupation. A phenomenology design also focuses on describing people's experiences of everyday life and "how it is that they experience what they experience."[67] This design gives great attention to the careful description of how the ordinary is experienced and expressed in the consciousness of individuals and is one of interactive dialogue and exchange, as the researcher seeks to know what the experience is like for the individual in his/her natural setting.[68,69]

3.2.2 The research setting

The research setting is a LSEN school situated in the Cape Metro-pole within the Western Cape. It caters for learners with a diagnosis of CP and learners who experience various barriers to learning. Learners are from economically disadvantaged communities. The school follows a mainstream

curriculum with Afrikaans and English as the mediums of instruction. The researcher has been employed there as a full-time occupational therapist for the past nine years, working primarily with learners in the foundation phase. She is also involved with the placement of senior learners in protective work environments.

The researcher has an interest in the quality of life of learners who exit school and has appreciation for the problems that they might experience, known to her through informal conversations with them. The researcher had the following assumptions and preconceptions about these ex-learners: Most of them do not cope with the demands of young adulthood; they have not been prepared adequately for life after school by the school itself; some might need extra support in order to maintain full-time employment and they are not socially integrated within their communities. Her knowledge of the learners themselves, the background of the school and her own professional view point as an occupational therapist, will inform the researcher's inclination of how she thinks about her study population.

3.3. Target population and sampling

3.3.1 Target population

The study population was young adults with a diagnosis of CP who attended the previously mentioned LSEN school and who have left school over the duration of the past nine years. The exit age for learners will differ, because in 2007 learners in schools catering for special needs were expected to leave the school at the age of 18 years.[70] Previous to 2007, learners' exit age was 21 years, implying that learners who left nine years ago would be 28 years old now. Therefore the participants of the study were young adults between the ages of 18-28 years. Written consent was requested and granted from the Western Cape Department of Education (Appendix A) and the school principal to screen ex-learners' files for information.

3.3.2 Sampling

The researcher used purposive maximum variation sampling. This ensured that variation in terms of diagnosis, living arrangements, employment and marital status was included. In qualitative sampling, purposefulness is intentional, as participants are selected because they can provide "rich information."[71] Information- rich cases are those whom the researcher could gain the most in-depth and insightful understanding from about the phenomenon, being their experience and meaning derived from their participation in occupations and ability to communicate these experiences.[67,71] Before purposeful selection began, the following criteria was used to select possible participants from a pool of 328 ex-learners.

3.3.2.1 Selection criteria:

- Participants had a diagnosis of cerebral palsy.
- Participants were between 18 and 28 years of age, to accommodate all school leavers in the nine years that the researcher has been working there.
- Participants lived within a 100 km radius of the school, for cost and time saving reasons.
- Participants had all completed at least Grade 9 at this LSEN school, as this became the exit grade in 2007 at this particular school. Learners with Grade 9 enabled an in-depth interview, for they had the ability to more abstract thinking needed to respond to the interview questions.

The researcher purposefully selected participants according to their gender, employment status, living arrangements, diagnosis, romantic involvement and level of education, in order to ensure the biggest variety of information-rich cases. A profile of the participants will be given in chapter 4.

3.3.2.2 Sampling method:

The researcher manually reviewed 328 files and documented information in an Excel program. Only 105 ex-learners met the selection criteria. The researcher contacted all of these 105 ex-learners telephonically (see table 3.1 for the telephonic responses) and requested verbal informed consent (Appendix B-1) to complete a short questionnaire (Appendix B-2), in order to gather information about their employment, living arrangements and marital status. The abovementioned data was summarized in a Word document. Verbal informed consent was requested and granted telephonically, before these ex-learners received an invitation to participate in the study.

Table 3.1: Telephonic responses

Completed questionnaire & gave verbal consent	31
Completed questionnaire, but not interested	1
Wrong telephone number (the person no longer lives there)	20
No telephone number on file	10
Telephone number discontinued (either a discontinued ring or answering service saying that the number does not exist.	42
Deceased	1
Total ex-learners contacted telephonically	**105**

The information gathered from the 31 participants who consented, were summarized in a Microsoft Word table format. These 31 ex-learners were also informed that they could receive another phone call from the researcher to set up an appointment, if they were selected to be interviewed by her. The ten participants who participated in the study were called one or two weeks in advance to set up an appointment for the first interview at a time and place that were convenient to them.

3.4 Data collection

Face-to-face semi-structured individual interviews at a place that was convenient for the participants were used, as it encouraged the participants to be in a familiar environment and described their experiences in more detail allowing opportunities for the researcher to ask probing explorative questions.[72] Human behaviour can only be understood in context and cannot be separated from the physical, economic and socio-cultural environments in which a person functions.[73] Bracketing was used by the researcher to set aside her own assumptions, in order to listen and hear the experiences of the participants.

As a participant in the data collection process, the researcher had to reflect on the frame of reference she is bringing to this process and applied the principles as described by Finley[65] in the work of Husserl, Heidegger, Merleau-Ponty and Shutz, throughout the duration of the data collection and analysis phases. To ensure:

- A focus on the life world or Lebenswelt ("the world of experience as it is lived"), by interviewing participants as far as possible in their own environment.
- A commitment to description over explanation, by asking open-ended questions during the interview, describing the experiences of the participants and presenting the findings in the form of themes with direct quotations from the participants.
- The use of phenomenological reduction and Epoché, by putting aside her own assumptions and previous knowledge about the participants.
- An attempt to retain a non-judgemental attitude, by recording exactly what the participants express about their experiences, without judging them.
- An acceptance of a role for interpretation.
- The concept of intentionality, by understanding that we as humans are "actively engage" in and with our world.

3.4.1 Data collection method: Interview

An interview guide (Appendix C) was developed from a framework of open ended questions derived from the literature, so that each participant was interviewed using guiding questions, which pertained to their experience of daily occupations.[68,74] A pilot study was conducted with 2 young adults with CP, working at a centre for physical disabled adults within close proximity of the school where the researcher works. They were not ex-learners of the before mentioned LSEN school, so therefore not part of the 31 ex-leaners who consented telephonically. The pilot study assisted the researcher, through the process of reflection, to enhance the effectiveness of her interviewing techniques and refine the interview guide for framing of questions.[73,75] Van der Walt and Van Rensburg[76] advise researchers to ensure that questions are short, simple, understandable and stated in an positive manner.

Ten interviews were conducted in Afrikaans or English (as preferred by the participants) by the researcher. A second interview was conducted with two of the participants, as further clarification was necessary. Six of the participants chose to be interviewed at their homes, two at a restaurant of their choice, one at work and one at school. Ulin, Robinson and Trolley's[71] stages of interviewing informed the interview process. The researcher applied these stages as follow:

1. Created a natural involvement by starting the interview with general conversation, by expressing her gratitude for their interest in participating in the study and by asking non-threatening questions first: "Could you describe a typical day in the week?"
2. Showed understanding by empathizing with what the participants was sharing with her and by sometimes relaying some of her own personal experience, when relevant.
3. Got facts and basic descriptions, by encouraging longer and more detailed answers as the interview progressed and probed when necessary.
4. Asked the really difficult questions (more abstract) towards the end of the interview: "How do you view your life now?"
5. Toned down the emotional level after some of the participants got worked up about their circumstances, by asking them if they have any questions for the researcher and by ensuring them about the confidentiality of the information.
6. Closed the interview while maintaining contact, by thanking the participants and confirming that the researcher might want to follow up to ensure that she understood them correctly or if she wants more information to enhance her understanding of their experience.

The researcher audio taped nine of the ten interviews, as it is the most effective way to document the participants experiences accurately and the researcher could give her full attention to the conversation.[73,77] One of the participants requested that a tape recorder not be used, as she

dislikes hearing her own voice, because of her speech difficulties. The researcher took manual notes of the interview and the participant also gave her one typed up page titled “My life after school”, which she completed before the researcher arrived. For the first two interviews a cassette tape recorder was used, but after stopping repeatedly to record in the beginning of the third interview, she switched to a digital recorder. The researcher ended the first interview and rescheduled another interview, which was recorded using a digital recorder. Field notes were kept in addition to the tapes to record the researcher’s unstructured observations.[76] This was filled in immediately after the interviews, when the researcher’s observations and impressions were still fresh in her mind. The field notes were descriptive and included everything that the researcher believes to be worthwhile, as described by Patton.[67] The researcher adapted a checklist for recording field notes, from Hammell, Carpenter and Dyck.[73]

Data saturation was reached with the tenth interview, when no new information emerged. This decision was informed by what Patton[67] stated that there are no rules in terms of sample size for a qualitative study and Hammel et al.[73], which proposed that the number of participants should not be determined beforehand, as the actual sample size is dependent on the quality and completeness of the information gathered.

3.5 Data Management and analysis

Several authors emphasize the fact that analysis starts when the first data are collected and this will guide further data collection.[68,78] Interviews were transcribed verbatim by the researcher. She found Henning, Van Rensburg and Smith’s[79] view of this to be very true, as they suggest that beginner researchers do their own transcriptions, because it help them to stay in close contact with the data. Ulin et al.[71] realize that in order to ensure “insightful and powerful analysis” it is necessary to take time to transcribe interviews verbatim. Between 5½ to 8 hours were used to transcribe an interview.

Inductive content analysis was utilized to analyse data. Henning et al.[79] found this to be the favoured choice of beginner researchers, as it works on one level of meaning. The researcher used hand coding rather than computer programs. All the transcriptions were printed with double line spacing and a 4 cm wide margin on the right side. Then she read through all the completed transcriptions to get an overall impression of the content and used open coding to identify significant statements. These were highlighted with a colour pencil (one colour for each participant) and coded or labelled in the right hand margin. These codes or labels were then written on A3 size papers and taped to a wall in a square shape. This allowed for organization of codes into categories, sub-categories and eventually themes. The researcher could also go back to check

and re-check her categories and themes. Member checking was done via telephone with two of the participants, to verify the themes that emerged from the study. Peer review was accomplished during meetings with the researcher's study leaders, as well as at monthly support group meetings with fellow Masters students. Pseudonyms were used to ensure anonymity of the participants and their families. This brings us to the question as to how the researcher ensured trustworthiness and rigor during her research.

3.6 Rigour and Trustworthiness

Trustworthiness and rigor were ensured by including the following principles of credibility, transferability, dependability and conformability, as suggested in Guba's model for assessing trustworthiness.[80]

3.6.1 Credibility

Credibility refers to the researcher being confident about the truth of the findings for the participants and the context in which the study was done.[81] The researcher used the following methods to enhance credibility:

- Triangulation – the researcher used a variety of data collection methods, including interviews, field notes and observations.
- Member checking – two of the participants were contacted telephonically to discuss the forthcoming themes and to verify the researcher's interpretation and conclusions. The researcher read the themes and subsequent categories and sub-categories to them and this was followed by a discussion.
- Peer debriefing – the researcher discussed her findings and progress during regular meetings with her study leaders, as well as support group meetings once a month with fellow Masters students.
- Reflexivity – the researcher kept field notes about her observations and her feelings, which was completed after each interview. She also kept a diary to reflect on her own emotions and experiences, which helped her to maintain objectivity throughout the whole process.

3.6.2 Transferability

Transferability refers to the degree to which the researcher's findings can be applied to other contexts or participants.[69] The researcher ensured transferability by using the following two methods:

- Purposeful sampling – the researcher used maximum variation to ensure variation in terms of gender, diagnosis, living arrangements, level of education, employment and marital status.
- Thick description – the researcher used semi-structured interviews to collect as many data about the phenomenon as possible. She then tried to describe her participants and their circumstances as detailed as possible, in order for the reader to understand the context of the participants.

3.6.3 Dependability and Conformability

Dependability refers to the research process and findings being reliable.[69] Conformability is the "degree to which the findings are the product of the focus of the inquiry and not the biases of the researcher."[69] Lincoln and Guba[80] propose the technique of inquiry audit to enhance dependability and then Babbi & Mouton[69] suggest using a single audit (if properly managed) to determine both dependability and conformability, as the latter part of the technique also establishes conformability. The researcher ensured dependability and conformability by the following method:

- Inquiry audit – the researcher kept an audit trail by documenting feelings and experiences in a reflexive journal; recording interviews on audiotape; keeping field notes of researcher's observations and transcriptions of interviews. Questionnaires which were completed over the phone, informed consent forms, the interview guide and themes that were developed are also kept on file. The above mentioned documents are also stored on external memory devices. The researcher also took photographs of the wall where the codes, categories and themes of the study were indicated on. All the above is in line with the ethical principles that guided the study.

3.7 Ethical considerations

This research study was approved by the Health Research Ethics Committee (HREC) at Stellenbosch University (Ref. nr. N10/09/315) on 26 November 2010 (Appendix D). The study was conducted according to the ethical guidelines and principals of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for research. The following ethical principals guided the study:

- The right to self-determination was ensured by obtaining written informed consent (Appendix E, F) from the participants and by upholding transparency in terms of the objectives of the study. At the first interview participants were given a chance to read the informed consent form, after the researcher explained it to them.

- The confidentiality of each participant was ensured by using pseudonyms and by keeping records in a locked filing cabinet at the researcher's home for the duration of the study and it will be kept at the Division of Occupational Therapy, SU for a further three years after the completion of the study.
- Autonomy was ensured by informing participants that they could withdraw at any stage during the study.
- The researcher ensured quality research by keeping thorough and complete documentation of the research process and results: being accountable for the appropriate dissemination of the results and recommendations and ensuring that the research is meaningful and contributes to the improvement of occupational therapy practice.

The research will be documented according to the requirements of the Faculty of Health Science at Stellenbosch University, in partial fulfilment of the Masters in Occupational Therapy programme. Results will be presented to the school involved and at conferences or in-service training sessions for therapists. An article will be submitted to the South African Journal of Occupational Therapy, as well as to the South African Neurodevelopmental Treatment Association's quarterly newsletter.

3.8 Summary

In chapter three, the researcher presented a detailed discussion of the qualitative methodology, including study design, population, sampling methods, data collection, data management, rigor and trustworthiness, as well as ethical considerations. In chapter four the reader can look forward to obtain an in-depth understanding of each participant and the four themes that emerged from the data.

CHAPTER 4: FINDINGS

A detailed description of the participants and the findings of the study will be discussed in this chapter. The reader will obtain a better understanding of each of the ten participants and their social context. The profile of participants will be looked at first, before the findings of the interviews according to the four themes which emerged from the data analysis will be discussed.

4.1 Discussion of participants

The profile of the participants is summarized in table 4.1 and indicates the following demographical information: age, diagnosis, employment status, education grade completed, marital status, spoken language and living arrangement. After the summary of the participants' profile, the researcher will share information to contextualize the participants. The researcher's own reflections and impressions are also documented here. Pseudonyms have been used for the participants and their family members, to ensure confidentiality.

Table 4.1: Summary of Participants' Profile

Participant	Age in years	Diagnosis	Employment	School qualification	Marital Status	Language	Living with or / in.....
1. Precious	25	Spastic Quadruplegia	Unemployed	Gr. 9	Married	English Afrikaans Xhosa	Group home
2. Thandi	26	Spastic Quadruplegia	Unemployed	Gr. 9	Single	English Xhosa	Group home
3. James	25	Spastic Diplegia	Full-time	Gr. 12	Engaged	English	Parents
4. Kevin	21	Hemiplegia	Full-time	Gr. 9	Single	Afrikaans	Mother
5. Rabia	24	Hemiplegia	Unemployed	Gr. 12	Single	English	Parents
6. Suzie	26	Hemiplegia	Part-time	Gr. 11	Single	Afrikaans	Parents
7. Billy	27	Hemiplegia	Full-time	Gr. 12	Single	Afrikaans	Parents
8. Andy	23	Hemiplegia	Part-time	Gr. 9	Single	Afrikaans	Parents
9. Stacey	27	Spastic Diplegia	Full-time	Gr. 12	Single	English	Parents
10. Nomsa	21	Spastic Diplegia	Part-time	Gr. 12	Single	English Xhosa	Mother

4.1.1 Precious

Precious is a 25 year old married woman who completed Grade 9 and is fluent in Xhosa, English and Afrikaans. She lives in a residential group home for adults with physical disabilities, with her husband of five years. The home consists of single rooms with shared bathrooms, a general dining and recreational room. All her meals are prepared in the home's kitchen, but sometimes she asks one of the carers to prepare a microwave meal in her room. She has the following furniture and equipment in her room: A television, fridge, double bed, microwave, kettle, small basin, build-in cupboard, dresser with a mirror and a chair. She is dependent on carers for most of her basic self-care, but can operate her electric wheelchair independently. The home offers quarterly social events as well as regular recreational activities. Precious prefers to spend time in her room and choose not to attend most of these events. She does not work, because her husband prefers that she stays home. Most of her day is spend watching TV, listening to music and playing with her cell phone. Her husband works for the home, selling tickets for fundraising events. He leaves home early in the morning and arrives back home around 19h00. Precious does not engage in any hobbies. On Sundays she and her husband are picked up by Dial-a-ride and taken to church. This is one of the highlights of her week. They manage their own money, paying rent, buying their own groceries and toiletries. Her mother and sister visit her regularly and she sometimes goes to her parental home for a weekend, as her home is now the residential group home, where she lives with her husband. Precious seemed happy and content with her life and accepts things as is.

4.1.2 Thandi

Thandi is a 26 year old single woman, living in a group home for adults with CP. She uses an electric wheelchair and can perform some self-care tasks with minimal assistance, but prefers to be assisted maximally with all self-care activities. She enjoys shopping for her own toiletries and certain food items. Each resident have their own room, but share a bathroom. All the meals are served in a communal dining room at set times. The rooms are spacious and Thandi's room is furnished with a bed, fridge, dresser, mirror, built-in cupboard and a computer desk (with computer and printer). Thandi spends most of the day on her or her friend's computer, making CD's for other people or surfing the net for jobs. Sometimes she goes to the shop on the corner with her electric wheelchair. She completed a computer course after Grade 9 and desperately wants to do computer work. She is currently not working, because she's looking for a job where she can use her computer skills. Since she left school, she only worked for one day at a protective workshop and quit, because it was boring. She does not like living at the group home and "hates" her life there. She would love to move back to the previous group home, where she left all her friends and love of her life. According to her, she is extremely frustrated about her physical, mental and financial situation.

4.1.3 James

James is a 25 year old young man, who completed Grade 12. He works full time at a gym and currently study on a part-time basis to become a personal trainer. He uses public transport to get to work and is independent in all areas of his life. He and his younger brother live with their parents in a two bedroom house. His mother works full time as well, while his father is unemployed at the moment. This is the reason why his father can accompany him to his athletic practices. He is involved in athletics on a provincial level and competed in the 2004 Para-Olympics. James seemed very confident and was not shy to talk about his achievements in life. He has a girlfriend of three years and has an active social life. Part of his community involvement is teaching touch rugby at a High school. James felt that the future is promising, as he is setting his eyes on competing at the Para-Olympics and possibly moving in with his girlfriend.

4.1.4 Kevin

Kevin is a 21 year old young man who completed Grade 9 and lives at home with his parents. He has been working at a protective workshop for the past 5 years. Kevin performs all of his self-care tasks independently, although it takes him longer to do it. He receives a disability grant and gives most of his money to his mother to assist with household expenses. Kevin loves his job and has more meaningful relationships with his colleagues than his family. He is unhappy living at home and would like to move out if he can. He used to play soccer for Western Province, but stopped since he left school. He does not have friends outside of work and spends most of his time over weekends with his girlfriend.

4.1.5 Rabia

Rabia is a 24 year old young woman living with her boyfriend and two year old daughter at her parents' house. It is a two bedroom house shared with her sister and her four children. Rabia and her boyfriend live in one room. She is thinking about moving to her father, but is still weighing up the pros and cons. She completed Grade 12, after which she was involved in a yearlong learner-ship. She then worked as a personal assistant for six months, before quitting the job, due to being pregnant. She is currently looking for a job, because she feels it is too difficult to survive on her disability grant of R1, 200. Rabia feels she has no social life since her daughter was born and spends most of her time at home with her.

4.1.6 Suzie

Suzie is 26 years of age and lives with her parents. Her brother and sister are both out of the house. She goes everywhere with her parents, but is currently working on attaining her driver's

license. She is independent in all her activities of daily living. Suzie completed her Grade 11 and started working at a protective workshop. She did not enjoy it and went to study business administration at a college, without success. For the past three years she has been employed by her aunt, working at a library. She does not enjoy her job, because it is not stimulating enough. She puts stickers in the books, but feels that she can utilize her computer skills very well if she is given the opportunity. Suzie also feels that she is being treated unfairly at work, but accepts it as she does not want to lose her job. Although she is quite involve in church activities, like singing in the choir, she does not have any friends to socialize with. She dreams of meeting someone special to spend the rest of her life with.

4.1.7 Billy

Billy is a 27 year old young man who completed Grade 12 and is independent in most areas of his activities of daily living. He needs help with tasks like tying his shoe laces and making his bed. His parents assist him with those tasks, as he lives in a Wendy house on their property. His father transports him to work every day. He works as a switchboard operator at the municipality of a small west coast town. He has a close knit family and they spend most of their weekends together, going places. He has friends who implicitly enjoy participating in the same leisure activities as him. Billy attended college for a year after school, which was sponsored by the Department of Social Development. He worked at two other organizations before starting his current job in 2008. Being involved in community work is very important to him and he is currently serving on the “Community Police Forum”, as well as volunteering where he can. He is currently busy doing courses to qualify himself as an assessor.

4.1.8 Andy

Andy is 23 years old and lives with his parents and older sister in a small west coast town. He completed Grade 9 and is currently working at a gospel music store in a shopping mall. He enjoys his job, because he interacts with people all day. Andy sings very well and would love to have a career in singing. He is actively involved in his church, as well as the community and spends most of his time doing that. Some of the activities are: being a conductor for different choirs, assisting others in the community by doing their shopping or tasks around the house and reaching out to other people in need like, those addicted to drugs.

4.1.9 Stacey

Stacey is a 27 year old young woman with a Grade 12 qualification. She completed a six month learner-ship in business administration and has been working as a registry clerk at a government

hospital since 2009. Her job is very important to her and she enjoys every aspect of it. She is engaged and has an 18 month old daughter. Stacey lives with her parents and younger sister in a house they are renting with the option to buy. She enjoys the fact that she and her daughter have their own room. She contributes liberally to the household expenses. Stacey's mother quitted her job to look after her daughter. She likes to socialize with her friends, but feels her lifestyle has changed since she became a mother. She is more content now to have friends over at her home versus going out to clubs. Stacey is currently working on attaining her driver's license and is hoping to buy her own car after that.

4.1.10 Nomsa

Nomsa is a 21 year old young woman who lives with her mother and completed Grade 12 in 2009. She works on a part-time basis at a leading retail store as a beauty consultant. Nomsa uses public transport to get to work and is independent in all her activities of daily living. She is proud of her job, although she only works up to eight hours a week. She and her boyfriend have been together for three years. Sport has been a big part of her life so far, as she participates in athletics (discus and shot put) for Western Province. She is thinking about giving it up, as she feels it takes up too much of her time. She is dreaming about studying further in the beauty industry with the hope of starting her own business.

Nine of the interviews done with the above mentioned participants at a place of their choice were transcribed verbatim by the researcher and documented in a Microsoft Word file. One participant did not give consent for taping the interview, using a tape recorder and the researcher therefore took manual notes. Data was analysed using inductive content analysis and the following themes, categories and sub-categories emerged, which will subsequently be presented schematically in figure 4.1.

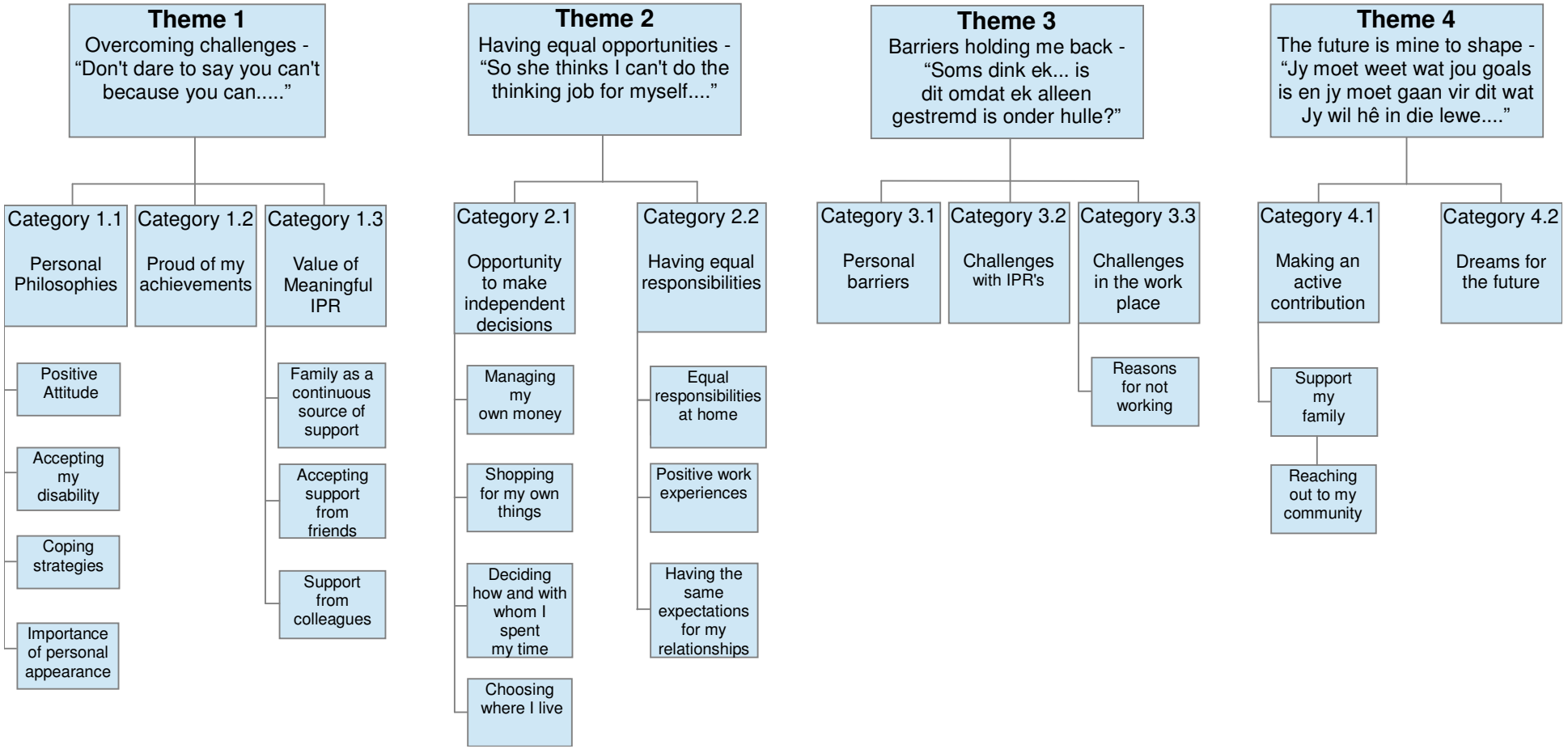

Figure 4.1: Summary of findings

4.2 Data Analysis

A detailed discussion of the four themes that emerged from the data analysis will follow below. Direct quotations from the interviews are used to illustrate and explain the themes according to the categories and sub-categories. The quotations that are provided here are not comprehensive of all the quotations that were used to determine the themes.

4.2.1 Theme 1: Overcoming challenges – "Don't dare to say you can't, because you can..."

Living with a permanent disability has various challenges and for some it is a daily struggle, while for others it is just part of who they are**.** All the participants had different ways of dealing with their challenges or disabilities. Although their circumstances varied greatly, they all found strength in similar things, to different degrees. These were: the value they found in meaningful relationships, their personal philosophies about life, how they view their life and being proud of their achievements.

Table 4.2: Summary of theme 1

Category	**Sub-category**
1.1 Personal philosophies	1.1.1 Positive attitude 1.1.2 Accepting my disability 1.1.2 Coping strategies 1.1.4 Importance of personal appearance
1.2 Proud of achievements	n/a
1.3 Value of meaningful relationships	1.3.1 Family is a constant source of support 1.3.2 Acceptance and support from friends 1.3.3 Support from colleagues

4.2.1.1 *Category 1.1: Personal Philosophies*

"Don't dare to say you can't, because you can...." This quote by Precious is an illustration of the positive attitude that most of the participants adopted in their life. This is the way they have overcome many challenges and obstacles in their young lives. Being determined to prove other's wrong in their preconceived ideas about people with disabilities and having confidence in their own abilities, are some of the ways they have coped with living with a disability.

Sub-category 1.1.1: Positive attitude

A positive attitude is a characteristic many of the participants acquired, because it became the way of coping with difficulties. Several of the participants have the attitude of doing things for themselves, instead of waiting on others to assist them. Some felt that they are just as capable as other people without a disability and don't need to feel insecure at all.

> *Ek is nie 'n person wat sit en iemand anders vir my doen nie.....ek doen 'n ding vir myself. Ek wil net sê my mission statement in life is: As jy dit nie vir jouself gaan doen nie, wie gaan dit vir jou doen? (Billy-p9)*
>
> *....if you don't take chances in life.....people....you going to sit, hey. You can't wait for other people. I'm waiting for my brother to come here. You never gonna get things done, because you always waiting for somebody else to do it for you. (Rabia-p8)*
>
> *That's why I always challenge able people.....always challenge able people...whatever you do ...Ek kom vir jou. That's actually my end view of life. I go there and do what I have to do. (James)For me I promise you, everything anyone do, I can do. No I don't feel excluded....in no situation....no way. (James-p3)*

Precious is very proud of the fact that she is married and by doing that she proved to others that she can achieve something through her determination.

> *....My wedding.....and my marriage life, because I actually proved to myself that I can do it and to a lot of people.....I proved them wrong, because they were looking at me as if: "How can you?" Now I have proved to them that I can. (Precious-p10)*

Sub-category 1.1.2: Accepting my disability

Accepting their disability is one of the personal philosophies which helped many of the participants in moving forward with their lives and dealing with the many challenges some of them face on a daily basis. Accepting their disability also means accepting what they cannot do, being thankful for what they can do and trying to make the best of their situation.

> *And in my life I'm actually calm about things I used to work myself up for that I can't do it or should do it or I like.....I'm actually more at ease with myself....now. And the things that I can't do I just actually just leave it and because I can't do it. It's no use working myself up for it. For sometimes we tend to work ourselves up for things that are unnecessary sometimes. (Precious-p11)*
>
> *A lot of people here don't understand why I'm so happy all the time. I think a lot of people see being disabled as a death sentence, but I understand why they feel like that.....most of the people here are disabled because of accidents and stuff.....but I was born this way, so I don't know anything else. (Precious-p12)*

Sub-category 1.1.3: Coping strategies

Using humour is one way Precious and her husband, both severely disabled, cope with the difficulties they encounter on a daily basis. Very few people would laugh about not being able to do certain things, but they have learned the art to see the funny side in everything they experience. One of the participants allows strangers to assist her on public transport in order to maintain her independence.

> *Like we would..... make fun of everything, although it's for some people sad, we would laugh about it and just joke around. (Precious-p9)*

> *Sometimes.....as ek op die bus klim, wag hulle eers.....hulle ry nie sommer nie. As ek afklim weer, wag hulle tot ek klaar reg afgeklim het voor hulle ry.....hmmmm. As ek weer met die taxi ry, vra hulle die person wat voor sit om hulle plek vir my te gee. (Nomsa-p1)*

Sub-category 1.1.4: Importance of personal appearance

Looking neat and smart was important for most of the participants. According to one of the participants, your whole manner, including your grooming, dress code, speech and non-verbal communication play an important role in how others view you.

> *But when you go out, you must always be neat....you hair, it must be tidy. Because why first impressions always last.....first impressions are lasting. If they don't know you, they look at your clothes, the way you react and they look at the way you speak. (Rabia-p1)*

Those who work felt they needed to be dressed in a presentable manner since they work with clients or customers.

> *My grooming is fairly, hmmm....how can I say.....respectful towards my clients, because you can't look like kippy or like that, cause why your clients like to you for motivation. (James-p1)*

> *Ek hou daarvan om myself soos hulle sê netjies en deftig aan te trek, want dis soos ek geleer het by die werk. Jy werk elke dag met die publiek, so jy moet leer om netjies voor te kom. (Billy-p2)*

4.2.1.2 Category 1.2: Proud of my achievements

Participants spoke proudly about what they have achieved in life in spite of their disability. For some it was studying further, having a good job, excelling in sport and getting their driver's licence. For others it was simply their independence from their family and being admired for it. Some of the participants had the opportunity of furthering their skills through studies, short courses and learner-ships. They were all extremely grateful and proud of this achievement, as it equipped some to get a good job and gave others the skills to become independent.

.....Not long after that, I start to work at Pick and Pay and then after that I went to study for six months at Siyaya Skills in Claremont. That was actually a wonderful experience.....studying business administration and of course when we completed that, you were placed in all different departments. I think that's a milestone.....that I'm independent not dependent on my parents anymore for anything. (Stacey-p5,6)

I went on one (tournament) last year.....in.....we went to PE for Western Province....then I came back with two gold medals for shot put and discus. (Nomsa-p3)

Ek leer nou vir kar lisensie en ek kan ry, maar net 'n bestuurder wat 'n kar kan ry moet saam met my ry as ek iewers wil gaan. En die 27ste Julie is my toets by verkeers en ek hoop ek slag, sodat ek my eie kar kan ry en..... (Suzie-p2)

4.2.1.3 Category 1.3: Value of meaningful relationships

Most of the participants emphasized the importance of supportive family, friends and colleagues that they can depend upon for help at any time. Three sub-categories came out from this category, namely family being a constant source of support, being accepted and support by friends and support from colleagues

Sub-category 1.3.1 Family is a constant source of support

Participants identified their families as the people who supported them continuously on an emotional, physical and financial level and who accepted and guided them when needed. They realized that some of their family members made sacrifices to assist them to accomplish certain things in life. As most of the participants still lived with their parents, they were even more grateful for their continued understanding, unconditional love, care and support. One of the reasons why family is important to the participants is their unconditional acceptance of them as individuals and being treated as "normal" people by their families.

My....mom....because if it wasn't for her I wouldn't have been here. Then I would not be who I am today, because of her. And she....sy't my aanvaar soos ek is. Dit was challenging for her .....om 'n gestremde kind te hê and sy't nie geweet waantoe nie en sy't rondgevra hoe.....sy't rondgevra eers. Sy't my aanvaar soos ek is en support and I passed matric two years ago because of that.(Nomsa-p4)

She's now 13, but I see me as the baby sister and she's my big sister. I can say to her: "Do this for me or do that for me" and she does it. And with me being disabled, she doesn't see me as a person in a wheelchair. And she would say to her friends when they want to make fun of me.....she would say to them: "No, this is my sister. You don't dare make fun of her." She's like my support system. (Precious-p9)

The participants' parents also played a vital role in guiding them to make the right decisions about their relationships, finances and careers.

> *My mother....simply because she gave birth to me and even now I can go to her anytime for advice and like for things I can't figure out. Even now that I'm married I can I still do that. I always tell my husband: "There's nobody that can take my mother's place." (Precious-p9)*

> *En as ek miskien iets verkeers gedoen, dan het hulle gewys die pad en nou soontoe, nie so maak nie...maak so....dis hoekom hulle vir my belangrik is...hmm...ek is baie lief vir hulle en dis hoekom hulle is belangrik vir my en kosbaar. En dit wat hulle vir my geleer het wil ek net terugploeg.....wat hulle vir my geleer het alles. Wil net sê ek waardeer dit. (Andy-p6)*

Receiving emotional support from their families, helped participants to look beyond their disability and motivated them to pursue their goals.

> *Sy't (my suster) my eintlik gewys hoe om ver te kom in die lewe. En ek kyk ook eintlik op na haar en sy vertel my ook altyd moenie moed op te gee nie en sy's lief vir my. En soos altyd bv. as ek miskien siek raak, versorg sy my en as ek nie uit die bed kan kom nie en voel nie lekker nie, sal sy altyd vra of ek okay is. (Andy-p7)*

> *Die rede hoekom, want hulle het my inspireer en hulle is die mense wat my gebring het tot waar ek vandag is. As dit nie vir hulle was nie, sou ek dit nooit....ek sal nie se ek sou dit nie gemaak het nie, maar.....(Billy-p7)*

Some of the participants pride themselves in their independence in terms of their daily activities, while others were extremely appreciative of their parents continued support to perform these tasks optimally:

> *.....en dan my klere nou stryk.....dit doen my ma vir my en my kooi maak my ma ook op vir my. My veters maak my pa vas in die oggend as ek werk toe gaan. (Billy-p1)*

> *Net soos ek gesê het....kerksdae miskien....choir practice gaan ek, maar dis so orals, dan in Florida, of in Belhar, of in Uitsig, of in Northville, ma ek's bly dat my pa my kan neem as dit so is. (Suzie-p6)*

Seven of the ten participants felt that they could rely, to different degrees, on their families for financial support when needed. For some it is actually borrowing money to buy what they need, while for other participants, it's having luxuries paid for by their families.

> *My sister who's here, she does accounting working and she just said that if the course were more than R 5,000, then she won't help, because she's already paying my phone bill. And because I get R 200 airtime and 25 sms's.....I first got R 150, then she changed it to R 200. (Thandi-p7)*

Ek sal nooit ooreis nie en as ek kortkom in die maand sal ek altyd met my ma gaan praat en sy sal altyd vir my geld gee, of.....vir my sê dat sy sal dit nie vir my kan gee nie.....ek verstaan dit..... (Billy-p3)

Sub-category 1.3.2: Acceptance and support from friends

One of the most important aspects of friendship is being accepted for who you are and being believed in. This is something that came out quite strongly in most participants' views of their friendships, including romantic relationships. Participants felt that their true friends looked past their disability, accepted them just as they are and motivated them to reach their goals in life.

Because he (my boyfriend) accepted me for who I am and he still supporting me in all stuff I'm doing, in like.....now she's disabled, ek moet haar los nie....hy het altyd by my gestaan en toe ek my enkel geswik het, hy was altyd daar om vir my te help. (Nomsa-p4)

Ek geniet baie om saam met my vriende te wees, want dit is waar ek my inspirasie en motivering teen die einde van die dag van kom. Want ek was al deur baie dinge, soos met die assessor's kursus....hulle het vir my gesê: "Billy jy kan dit maak, moet dit nie drop nie." En dit was voor ek op die kursus gegaan het. Die kursus self is net 4 dae lank en hulle het vir my gemotiveer op die oueinde van die dag en hulle is die mense wat my eintlik gehelp het met die goed op die einde van die dag..... (Billy-p6,7)

Sub-category 1.3.3: Support from colleagues

Some of the participants felt that the friendships they formed at work are invaluable to them and a sure source of happiness. Being able to rely on your colleagues to assist you with certain tasks at work has been some of the participants' experience as well.

By die huis staan it stil en hie by die werk.....dis oraait hie by die werk, want hieso praat haa met iemand. By die huis praat jy nie...(Kevin-p7)

I have friends (at work) that I can say to: "look here, help the clients." And the clients are fine with it....I can't do it, so I pass it..... (James-p2)

4.2.2 Theme 2: Having equal opportunities – "So, she thinks I can't do the thinking job for myself...."

Participants all desired to be independent, have control over their lives and steer it in the direction they want to.

Table 4.3: Summary of theme 2

Category	Sub-category
2.1 Opportunity for autonomy	2.1.1 Managing my own money 2.1.2 Shopping for my own things 2.1.3 Deciding how and with whom I spent my time 2.1.4 Choosing where I live
2.2 Having equal responsibilities	2.2.1 Equal responsibilities at home 2.2.2 Positive work experiences 2.2.3 Having the same expectations for my relationships

4.2.2.1 Category 2.1: Opportunity for autonomy

Being able to make your own decisions and choose what you want in life is something that was very important to the participants, especially in the areas of finances, shopping, time spent and living arrangements. This was another way of proving their independence to their family and friends.

Sub-category 2.1.1: Managing my own money

For most participants the opportunity to spend their money the way they want was something that gave them a sense of freedom and independence. Most of the participants received disability grants, while some were not, as they were employed in higher paying jobs. Some had their own bank accounts, while others would give their money to their parents to manage.

> *Ek sal....ek sukkel op my eie. As ek nie by 'n ding kan kom nie, maak bv.ek wil die maand....maak 'n goeie voorbeeld die maand is daar 'n paar Adidas van R600, maar ek sien daar is nie nou geld, sal ek dit laat oorstaan en ek sal spaar tot ek by daai kan uitkom. (Billy-p3)*

Some participants were very aware of saving and spending their money wisely.

> *Well if money runs short...well if it really run short....I am saving at the moment, so I always have....if my money runs out. I just take from the savings. (Stacey-p2)*

> *Ek moet my geld balanseer....ek moet net my week se geld uithaal en die anders in die bank sit. (Nomsa-p2)*

Sub-category 2.1.2: Shopping for my own things

Most of the participants enjoyed the different aspects of shopping, i.e. spending their money on what they wanted, just getting out of the house or for the sheer enjoyment of browsing and buying. They mostly shopped for their own food, toiletries or clothes.

> *I do sometimes. Believe you me. Most of the time I do my own shopping my own food. But it is not compulsory. I don't actually have to do it, but I choose to. (Precious-p2)*

> *Ja, elke maand doen ek my eie grocery shopping. Ek gee vir haar 'n cut en sy moet dit wat sy wil shopping, maar ek koop wat ek wil hê. (Billy) Vir my is dit goed om van tyd tot tyd te gaan shopping...vir my is dit goed om van tyd tot tyd self te gaan shopping, want ek ....hoe kan ek dit nou verduidelik?.....joh.....ek weet wat ek wil hê, so ek weet waarna moet ek moet gaan soek.....(Billy-p2)*

Rabia's experience has been that people in general wants to assist her when they notice her disability, but she dislikes that. She feels she is very capable to do it on her own.

> *It's nice...cause I don't want people to feel sympathy or feels she needs help, but I don't want to sound rude like: "I don't need help", but I want my independence. (Rabia-p2)*

Sub-category 2.1.3: Deciding how and with whom I spent my leisure time

Spending time with their families and friends, are something the participants valued and it gave meaning to their lives. Going places, shopping, eating out, cooking together and reaching out to others in the community were some of the occupations they engaged in with their families and friends on a regular basis.

> *Naweke....ons (my familie) gaan meestal uit, ons is nooit mense wat by die huis sit nie. Ons gaan meestal na familie toe, my ouma bly in die Paarl...ons ry baie na haar toe en dan.....ons is 'n fun familie....ons hou nie daarvan om by die huis te sit naweke nie. (Billy-p1)*

> *Ja, as mammie en ek saam kook is dit bv. ek en mammie wat saam kook of ek en my pa kook saam, ja.....of ons sit saam in die huis of ons gaa na verskillende huise toe miskien waar mense siek is. .....Elke Donderdag doen ons huis godsdiens, waar ons bietjie oor die Bybel praat. (Andy-p7)*

I have two friends, who lives down the road. We go out drinking, have a good time....go to clubs.....the things that a young man do. (James-p3)

.....as ek my vriende gaan kuier.....ons is almal op die selfde vlak, want hulle rook en drink ook nie, dan gesels ons almal baie lekker, want dan weet almal waaroor om te gesels. (Billy-p6)

Spending time doing quiet activities were also quite common amongst the participants. They enjoyed watching television, surfing the internet, chatting on social networks and listening to music.

Vir my is dit lekker by die huis om op my foon te gaan, op Facebook en Twitter, met mense te gesels en te ontmoet. En om televisie te kyk.....ek wil nie Days of our lives, Bold en Sewende Laan en....mis nie. (Suzie-p7)

Some of the participants also experienced a difference in how they spend their time, after major life changes, e.g. becoming a mother and getting married.

We never do things together really...we use to go to the Waterfront and spend.....go to Century City and come home 24h00. We can't do that anymore. He (boyfriend) told me the other night: "You know I'm 29, but I feel 59." Then I said: "We never go out, watch a movie....." (Rabia-p5,6)

Sub-category 2.1.4: Choosing where to live

Of the eight participants who were living with their parents, six seemed content with the arrangement, while the other two thought it was time to move out and get their own places. One of the participants reported that she "hates" the place where she currently lives, because she doesn't have any friends there.

My brother already moved out of the house and the next step is I have to move out, because why.....I have to go out and do my own thing. (James-p5)

I hate my life here at ____ House.....I hate my life here at _____House, because I've been uprooted from all my friends. (Thandi-p6)

4.2.2.2 Category 2.2: Having equal responsibilities

Part of having equal opportunities is the privilege of sharing equally in responsibilities at home and work. Participants also had the same desires and expectations for their relationships.

Sub-category 2.2.1: Positive work experiences

Three out of the seven participants who worked, spoke with pride and excitement about their jobs. Loving what they do at work and being happy when at work are some of the reason why

participants had positive work experiences. They felt valued, as they were treated as "normal" people and given the same responsibilities as their colleagues.

> *I'm a registry clerk and I do....filing of government circulars. I'm actually acting secretary as well and PA.....so ja, I have to keep the boss happy. I work in all kinds of departments....they would give me things to file and I work at the switchboard as well....and relieve the guys on lunch and things like that. I also like answer the phones and relieves the CEO's secretary when she's on leave... (Stacey) I won't change anything.....nothing. I wouldn't change anything...I'm very fortunate. They don't treat me as a disabled person.....(Stacey-p3)*

> *Oraait....nee, geniet dit om daar te werk. Omdat ek lief is vir sing het ek maar gedink om by Gospel Direct te gaan werk. En ek geniet dit om te kommunikeer met mense en mense te help in die winkel.....om hulle lekker te laat voel as hulle inkom. By 'n plek waar almal vir my kry en vir my hallo sê.....ek geniet dit eintlik om daar te wees. (Andy-p3)*

> *And I have clients telling me like "yoh", like they told me the first time: "You can't train me because you limping." Ah it's cool, cause any day I can give them results. (James-p1)*

Sub-category 2.2.2: Equal responsibilities at home

For some participants having to do certain chores at home is just part of living at home, while others felt it was not their responsibility. This also made them feel that they are treated as everyone else and not excluded from certain things the rest of the family have to do. Two of the participants did not see the need to participate in household chores, as they shifted the responsibility to other family members.

> *My father is there to do that. (James-p2)*

Sub-category 2.2.3: Having the same expectations for my relationships

Being involve in a relationship, i.e. with family, friends, opposite sex or colleagues, means having certain expectations and placing certain values on that relationship. Most of the participants valued the same qualities in a relationship, e.g. honesty, trust, feeling loved and cared for.

> *And understanding.....like whether it's now in your marriage relationship or whatever. Understanding each other is the key to everything. And to be able to speak openly. If you don't like something, just say you don't like it, to prevent all that conflict and misunderstanding. You just have to learn to understand each other.....that's the key for me. (Precious-p10)*

Weet jy.....hmmm, daar's baie....vertroue, vertroue ten alle tye en vandat ek is nou weg van die ou se NGO...ek was op die bestuur gewees, maar daai vertroue band was gebreek.....hoe kan jy binne die vergadering besluit ons doen a, b en c en dan besluit ons buite ons doen f, g.....so vertroue is in die eerste plek 'n groot deel. Vertroue en hmmmmm hoe kan ek sê? Omgee vir mekaar. Jy moet wys dat jy gee om vir 'n ander person. Nie net dink aan self nie en jou alleen nie....(Billy-p8)

4.2.3 Theme 3: Barriers holding me back – "Soms dink ek....is dit omdat ek alleen gestremd is?"

The categories that emerged from this theme, indicate that some of the barriers participants experienced were internal (personal) and others external (relationships and work place).

Table 4.4: Summary of theme 3

Category	Sub-category
3.1 Personal barriers	n/a
3.2 Challenges with IPR	n/a
3.3 Challenges in the work place	3.3.1 Issues hampering progress at work 3.3.2 Reasons for not working

4.2.3.1 Category 3.1: Personal Barriers

Feelings of frustration, hopelessness and negativity were some of the participants' experiences. These feelings were caused by different circumstances and made them feel as if they do not have control over their own lives. Some participants felt their financial situation influence their outlook on life.

I'm extremely frustrated in three ways: financially, physically and mentally. I feel like I'm wasting my God given talents. .....It's like I can't even do the thinking job for myself. I hate that so badly! It's just like I haven't got brains for myself! (Thandi-p6)

I view it very, very negative lately, because it's frustrating when you don't have money. (Rabia-p8)

Ek doen boeke. Ek sit stickers in die boeke.....en.....dis al. (Suzie-p.1) Wat wil hulle hê....wil hulle my jaloers maak of.....Maar soos hulle sê: "Ons moet voortgaan, ons kan nie kwaadraak daarvoor nie.....(Suzie-p5)

4.2.3.2 Category 3.2: Challenges with relationships

Although most of the participants enjoyed ongoing support from their families, a few of them had the opposite experience, where family members made decisions, without consulting them, about certain important issues. Not having their own friends was a challenge for some participants, leading to feeling sorry for themselves and withdrawing themselves from social activities.

> *My mom likes to control my life, as a disabled woman and I hate it very much.....(Thandi-p.6) I know she's my mother and I will respect her. That's why I have stopped going home or asked her for money. (Thandi-p8)*

> *Ek het gehad....vriende, maar soos die lewe aangaan en hulle ook hulle eie goed doen en die boyfriends...as hulle boyfriends het, wil hulle ook niks met vriende te doen hê nie. Ek het 'n vriend hier in Belhar, maa vir hoeveel jaar het ek haar nog nie gesien nie, omdat sy 'n boyfriend het. (Suzie-p10)*

4.2.3.3 Category 3.3: Challenges in the work place

Being able to work was so important to some participants, that they were willing to stay in their jobs even though they were treated unfairly or experienced the demands too overwhelming. Another participant on the other hand felt that she would rather quit her job, than being treated unfairly.

Sub-category 3.3.1: Issues hampering progress at work

One of the participant's experiences had been that the physical conditions were so poor and what was expected of her, so unreasonable, that it jeopardized the safety of her unborn child. This led to her resignation. Some participants were not experiencing job satisfaction, due to their perception of being discriminated against, unreasonable demands and unsupportive supervisors.

> *I was a PA and after awhile she got lazy that she stayed off of work....Rabia kan die werk doen...dis fine. Rabia stoot kaste and then one day I went to the doctor and he said to me: "Your job or your baby, you choose one or the other.....you make the decision today. You can't push cupboard and carry boxes." I was working in a warehouse....it was horrible miss....it was stuffy and dirty. I think the geyser bursted three years ago and they never fixed it. It was mouldy and I had to work without a mask or gloves.....for R 1,500 a month...it's not worth it. (Rabia-p3)*

> *People in general they have the perception of disabled people....how to handle you. When I got there, they didn't know how to react.....they didn't know how to handle me. People themselves they classify other people. That was it, because here I felt like they going to accept me.....because I think when people hear you disabled they block out...they don't know how to handle you. (Rabia-p7)*

.....Jy deel met soveel mense se emosies en jy's skakelbord operateur en baie mense is onbeskof met jou oor die foon, so met al daai emosies wat jy nie kan verwerk op die einde van die dag nie en jy kan nie by jou supervisor gaan kla of wat nie, want hulle sê vir jou die mense kom eerste. Ja, dis baie uitputtend...en jou pose hou en daar's nie 'n musiek wat speel of 'n ding nie....dis net jy, jouself en die telefoon, dis al. (Billy-p5)

Sub-category 3.3.2: Reasons for not working

Three of the participants were unemployed for various reasons.

Hmmmm....let me put it to you like that. Cause my husband doesn't want me to. (Precious-p3)

I worked at Village for two days and then I just had to stop. The job was working on my nerves. (Thandi-p3)

4.3.4 Theme 4: The future is mine to shape – "Jy moet weet wat jou goals is en jy moet gaan vir dit wat jy wil hê in the lewe....."

The above quote from one of the participants is a beautiful summary of how some of them saw their future, indicating hope and opportunity for better things to come.

Table 4.5: Summary of theme 4

Category	Sub-category
4.1 Making an active contribution	4.1.1 Supporting my family 4.1.2 Reaching out to the community
4.2 Dreams for the future	n/a

4.2.4.1 Category 4.1: Making an active contribution

For some of the participants it was important to be able to assist their families and others in need. It made them feel that they had a purpose and was needed.

Sub-category 4.1.1: Supporting my family

Most of the participants who work spoke about their part in assisting their family members financially. They were doing it through either paying boarding fees or the rent and also lending money to their family.

Well. I think because my job is more stable, so my parents know that I'm always there for them.....I would do anything. I would give them anything, like paying the rent and things like that. (Stacey-p3)

Ja, like my younger.....my older brother and my younger brother when we sitting down for lunch....they always ask for my bank card. (James-p3)

Sub-category 4.1.2: Reaching out to the community

Being actively involved in their communities and the church was very important to some of the participants, while others felt they were not equipped to do that or simply never thought about doing it.

Ek is 'n baie gemeenskaps betrokke person. Ek was eerstens by ons Mooreesburg Jeug Aksie.....Ek was betrokke by 'n NGO, maar is weg vir verskeie redes. Ek is nou betrokke by onse GPF (Gemeenskaps Polisieëring Forum) waar jy kyk na veiligheid in die gemeenskap. So ek is betrokke by die GPF en dan doen ek maar vrywillige diens in die gemeenskap waar ek kan. So my werk stop nie eintlik half nie, ek gaan an daarmee by die huis. (Billy-p6)

Okay, soos bv. my auntie wat siek is by die huis en sy moet haar medikasie by die kliniek gaan haal.....sy kan nie nou mos loop op die oomblik nie. Dan gaan ek vir haar op die tyd wat sy die medikasie moet kry, dan gaan haal ek dit vir haar en ek bring dit vir haar huis toe of ek gaan help ander mense wat miskien siek is en ook sukkel om werkies te doen by die huis, dan gaan help ek vir hulle as ek af is by die werk. (Andy-p4)

Ons jeugwerkers, ons gaan besoek mense by verskillende kerke in die aande. .....en ja kyk na mense wat aan drugs verslaaf is en ons reik uit na hulle om vir hulle te laat voel dis nie nodig om dit te doen wat hulle wil doen nie en ja, dan gaan ons en ons besoek die mense wat aan drugs verslaaf is. (Andy-p5)

4.2.4.2 Category 4.2: Dreams for the future

Knowing what one wants in life and striving towards that goal is the most important thing in life. Having someone special in their life, was something three of the participants longed for. Improving their skills, either finding or changing jobs or increasing their independence, were some of the other dreams participants had.

Weet jy, dit is om sukses te behaal in die lewe, want sonder sukses kan jy nêrens kom aan die einde van die dag nie. Moet doelstrewend te wees aan die einde van die dag.....jy moet weet wat jou goals is en jy moet gaan vir dit wat jy wil hê in die lewe. (Billy-p9)

Ek wens eendag iemand spesiaal ontmoet wat ek kan vertrou en met wie ek kan gesels en altyd by wees en miskien my eie huis hê.....(Suzie-p10)

My dream is to be independent, not always dependent on family....because my family suck! (Thandi-p7)

Ek sien myself.....oppie TV, ja ek sien myself oppie TV, want as ek gedink het, ek het altyd gedink: "ek wil op die TV sing", ja so ek sien myself daarso. Om te sing, ja om my eie CD's te loop maak, my eie album te hê en songs te skryf. (Andy-p8)

4.3 Summary

The researcher gave an overview of the participants' profile and a detailed description of the themes, categories and sub-categories that emerged from the data. In chapter five a detailed discussion of the above results will be presented.

CHAPTER 5: DISCUSSION

5. 1 Introduction

To answer the research question, using semi-structured interviews, the following four themes emerged and will be discussed in this chapter with reference to similar studies in the literature, in order to have a better understanding of the experiences of the young adults living with CP, about their participation in meaningful occupations.

5.2 Framework

The researcher found the Person-Environment-Occupation Model (PEO Model)[36] a good model to use when analysing the study's four themes. According to the PEO Model the perfect fit between the person, their environment and the occupations humans participate in, leads to optimal occupational performance.[36] Occupational performance can therefore be defined as the "dynamic experience of a person engaged in purposeful activities and tasks within an environment."[36] As the aims of the study were, looking at the different occupations the participants engage in, the meaning they attach to these occupations and how they experience their participation, as well as the factors impacting on it, therefore the PEO model was used as the framework within which to discuss the findings of this study.

5.2.1 The Person

The information gained as emerged in the four themes of the study, will be discussed firstly under person; including roles, skills, values and beliefs; secondly under environment; including physical, work, socio-economic and community and thirdly under occupation; including self-care, work, leisure and spirituality. The person according to the PEO model is defined as a human being who takes on a variety of roles. It is viewed as having "composite mind, body and spiritual" characteristics, attributes and skills that play a part in their daily lives.[36] A person's values and beliefs influence how they perceive themselves in relation to occupation and environment, how they see and discover the world, as well as their relationships.[82]

5.2.1.1 Roles

A major stressor in the lives of young adults is coping with the demands of the different roles they have to take on.[28] Heard[83] found that having a chronic disability hampers the ease of acquiring roles. Most of the participants were fulfilling the roles of sibling, child and friend, two of a mother and one of a wife. All the participants had feelings of gratefulness towards their parents for giving

them the best they could, to make sure they got somewhere in life. Having the support of her parents on a daily basis helped one participant to cope with the demands of life and the different roles she had to fulfil.

For the five participants who were involved in romantic relationships, being a loving and understanding partner was important. Two of the participants were previously involved in relationships and two never had any romantic connection with anyone. This is in line with the results of Wiegerink et al's[61] cross sectional study. They found that most of the participants had relatively active dating skills and the vast majority had fallen in love at least once.[61] Only 23 % were involved in a romantic relationship, which were significantly less than the age-appropriate Dutch reference population.[61]

Occupational roles will be discussed under work occupations.

5.2.1.2 Attributes

Attributes include self-concept, personality style, cultural background and competencies. Some of the participants acquired a positive attitude towards life, while some allowed their experiences and difficulties to create feelings of negativity. Participants remained positive by proving their independence, making the most of their situation and setting goals for themselves. Two of the participants proved that practice makes perfect, as they experienced it with self-care activities like dressing. Some of the participants demonstrated their resilience through their go-getter attitude and felt they do not have to stand back for anyone.

Proving others wrong were evident from some of the interviews, as some participants tried deliberately to do that, while others felt they accidentally proved to others what they thought could not be done. One example was getting married in spite of having a severe disability. One young woman mentioned that she can be very stubborn in order to show others she can do things on her own. Participants' experience taught them that once they have acknowledged their own limitations and struggles, they were able to accept help from others or adapt the situation they were in to become as independent as possible.

5.2.1.3 Skills

One of the participants felt that her learner-ship equipped her with the necessary skills to get a good job and therefore increased her independence from her parents. Two of the participants were involved in athletics on a provincial level and spoke how their achievements have motivated them

to set higher goals for themselves. Two of the participants were in the process of attaining their driver's licences, which is a huge accomplishment for them, as they thought they would never be able to engage in such an occupation because of their disability. This is in line with the previous discussion in Chapter 2 on the developmental task of developing a life style during young adulthood.

5.2.1.4 Values and beliefs

Having equal opportunities and making their own decisions were something the participants felt very strongly about. Being able to do that helped them to be in control of their own lives. One of the participants spoke about her mother controlling her life, making decisions for her as if she does not have a brain to think for herself. This caused her to feel very frustrated about her life in general and suffered from depression. She was the exception, as the other participants made independent decisions in terms of their dress code, shopping, money, friends and leisure activities. This is similar to what Yeung, Passmore and Packer[84] found with their phenomenological study of young adults living with CP in Australia, on how they perceive their citizenship and the factors influencing their citizenship participation. One of the themes that emerged from their study was equal opportunity, as participants longed to be independent and want the right and power to control their own lives.[84] Making independent choices would assist them in living "their lives in such a way that they would feel empowered and valued by the experience."[84]

5.2.2 The Environment

According to the PEO model the environment is seen as the physical, social, political, economic, cultural and institutional space, including the person, their family, community, neighbourhood, province, country and the world.[36]

5.2.2.1 Physical Environment

The researcher will integrate the different aspects of environment within her discussion of the environment.

Living Arrangement

Eight out of the ten participants were living with their parents, either in the house or in a separate dwelling on their property. Only one of the young men was aspiring to move into his own flat. The others seemed content with their current living arrangement, as if their parents will always be there to take care of them. This is in line with what Donkervoort et al.[59] found, that 83% of young adults

with CP in their study were living with their parents. One of the participants living in a group home, expressed her extreme unhappiness with her living arrangement, as she was moved there by her mother. She felt she was "uprooted" from her friends and boyfriend she had at the previous home she lived at.

Work

The poor physical conditions at one of the participant's previous jobs caused her to resign. It was expected of her to move furniture, carry heavy boxes and working in a mouldy environment, while being pregnant. She also mentioned that one other working environment was not disabled friendly either, as she had to struggle climbing stairs to get to a toilet. Working as a music store salesman in a shopping centre had been a positive experience to one of the participants. Living in a small coastal town meant everyone knew him and would greet him coming into the store, contributing to the perceived meaningfulness of his job. For one of the participants working at a gym, his work environment was conducive to growth and increasing self-confidence, as he could depend on his colleagues to assist him with certain tasks. Thus the factors contributing to a positive environment for these participants were: friendly and helpful attitude of others; acceptance by and support from colleagues, where as the factors that influenced their work environment negatively were poor physical conditions and unreasonable demands.

5.2.2.2 Socio-economic

Most of the participants lived in economically disadvantaged communities, where it is common for a lot of people to live in one house and often with only one bread winner. In one of the households the participant's disability grant was the only source of income.

5.2.2.3 Community

One of the participant's experienced that people generally have a pre-conceived idea of how to handle someone with a disability. Yeung et al's[84] study participants as mentioned under the section "Values and beliefs" also experienced that society is ignorant and strange towards people with disabilities, causing them to have "negative images and attitudes." Living in the community does not warrant "participation or a sense of belonging."[84] Being robbed while walking to the shop was one of the participant's experiences and a rude awakening to her that people in her own community do not have regard for a person with a disability. One participant in this study had the opposite experience, as he voiced that people in his neighbourhood accepted him with his disability from childhood.

5.2.3 Occupation

In the PEO model occupations are defined as “groups of self-directed tasks or activities in which we engage over a lifespan.”[36] The participants were involved in a variety of occupations, in terms of work, self-care, household chores, leisure activities and involvement in their communities. These occupations had different meanings to different participants and what was not deemed important by one, was valued by another.

5.2.3.1 Maintainer of person: Self-care

Most of the participants were independent in the majority of their self-care activities, like bathing, dressing, grooming, preparing food, managing their money, transport and shopping for their own clothes, toiletries and food.

Bathing, dressing, grooming

One participant specifically mentioned that his mother irons his clothes and his father ties his shoe laces for him. Another young man also admitted that he struggles to tie his laces, prepare something to eat for himself and to dress himself. Two of the participants were totally dependent on others for their basic self-care needs. One of these young woman pride herself in being able to brush her own teeth and feeding herself finger foods. She expressed an attitude of acceptance, as she mentioned: “I just do it as I can.” The other participant though, could do some tasks with minimal assistance, but preferred others to do it for her, as she described herself as being “lazy”. She suffers from depression, which might influence her self-concept negatively and lead to a lack of intrinsic motivation to perform certain tasks.

Transport

Six of the participants reported that they are independent in using public transport, i.e. taking a taxi or bus, including Dial-A-Ride. One of the participants also used her electric wheelchair to visit the corner shop where she lives. Only one of these participants mentioned her experience as positive using public transport, as she found that people were very accommodating in general. The other four participants were being transported to work, friends and community outings by their fathers. Two of these young ladies were in the process of attaining their driver’s licenses.

Managing money

Most participants managed their own money. Some would give a portion of their income or disability grant to their parents and spend the rest as they wished. Only one of the participants

stated that he gives all his money to his parents and they advise him on how to manage it. Some of the participants mentioned working according to a budget, while others would buy what they want within their means. All of the participants, except two, said they could depend on their parents for financial assistance when needed. The other two participants stated that they will never ask their parents for money, for various reasons. Being too proud and wanting to prove their independence were some of these reasons. Seven of the participants received a disability grant, which currently amounts to R1, 200 per month. One of the criteria to qualify for the disability grant is earning less than R47, 400 annually.[85] For three of the participants this was the only income they had. Struggling to make ends meet on the disability grant was only mentioned by one participant, while another participant felt very frustrated because of her financial situation.

Shopping

All of the participants spoke about the excitement of shopping for their own clothes, food or toiletries. Some of their faces lit up with smiles when they started to talk about browsing the shops, especially the young women. They reported simply loving the experience. Even the participants living in the group home, preferred to sometimes buy their own food that could be prepared in their rooms.

Knowing what they wanted, especially in terms of their clothing, was one of the reasons why these young people preferred to shop for their own clothes. Some described the experience as “normal”, while two of the young women mentioned the fact that people always want to assist them when noticing their disability. They disliked it, as they feel very capable of doing it on their own.

Sleep

Having difficulty sleeping at night was reported by only one of the participants. She is taking anti-depressants at night to assist her to sleep, but according to her, she only sleeps for half an hour and then lies awake for the rest of the night. Being totally dependent on others for her care, this meant lying in bed until the next morning when someone comes to transfer her into her wheelchair.

As mentioned earlier, most of the participants were independent, with or without some assistance, in all the above mentioned areas of their self-care. Donkervoort et al’s[59] findings were similar with young adults living with CP. Most of them were living with their parents, meaning in a sheltered, secured and structured environment. Donkervoort et al.[59] argued that this might have been the reason why these young adults did not really experience difficulties in performing daily activities.

5.2.3.2 Family member

Household chores

Doing chores at home was part of a normal routine for most of the participants. They were responsible for cleaning their own space at home, as well as doing some of the other chores, including: cleaning the kitchen (washing / drying of dishes, sweeping, mopping, scrubbing pots), vacuuming the house, cooking, cleaning the yard and gardening. Most of them reported disliking doing the dishes, but enjoyed cleaning their own rooms, doing laundry, cooking and working in the garden. In a study of activity limitations in personal, domestic and vocational tasks, Andrén and Grimby[17] similarly found that activities related to household chores and transportation demonstrated the highest level of independence. Two of the participants mentioned that they were not involved in any of the household chores, as they felt there were other family members that could perform these tasks. Living in a group home, two of the participants have their rooms cleaned on a daily basis by staff.

Motherhood

One of the participants found the experience of motherhood very daunting and started feeling incompetent to take care of her child. Initially she had to rely on her mother and sister to care for her baby until she became more at ease with the tasks. She found that although her daughter is a toddler now, she still battles to juggle all the different activities revolving around her on a daily basis. The researcher struggled to find information on how young women living with CP experience motherhood.

Wife

Becoming a wife was something that was very overwhelming to one of the participants, to the point that she withdrew herself for a week, went to her mother's house and felt like she needed a break from this new responsibility. Her experience had been that their marriage is subjected to the same problems as couples without a disability.

5.2.3.3 Worker / employee

All the participants with a Grade 12 certificate, except one, were employed in full or part time jobs. Two of the participants who completed Grade 9 had full time employment, while the other participant with a Grade 11 certificate was employed on a part-time basis.

Paid employment

Most people with a disability who has the ability to work, desire to have a job because of the value it holds in society.[86] Having a job, filled most of the participants with pride and a sense of independence and belonging. This meant they could look after themselves financially, as well as support their families. They felt valued, because their colleagues treated them as "normal" people, looking past their disability and admiring their ability. Having part-time employment was not specifically linked to the participants' disability. This is in contrast to what Darrah, Magill-Evans and Galambos[87] found, when they explored the contribution of educational, employment, transportation and assured income service programs to the successful transition to adulthood of young adults with motor disabilities, living in Canada. After doing semi-structured interviews they came to the following conclusions: Fatigue and fluctuating health problems did not permit the participants to work on a full-time basis.[87]

For one of the participants working in a protective workshop, work was the place where he was happiest, as he had more support and care from his colleagues than his family at home. On the contrary, two of the participants did not experience job satisfaction at all. One of them mentioned that she perceived being treated differently to the other employees because of her disability, leading to fewer opportunities at work. She also had the perception that what she was doing at work was not important at all. The other participant also found that some of the demands at work seemed too high and having an unsupportive supervisor contributed to his frustration.

Although one of the participants was not working, she reported living a fulfilled life. She has never worked since she left school and currently it is her husband's preference for her to be at home. This is confirmed by Campen and Cardol[51] that there is definitely a relation between life satisfaction and work, but proves that work cannot be the only aspect of life satisfaction. Their study results indicate that "four out of ten people with a physical disability are satisfied without work."[51] In this study one of the participants with a severe disability, expressed her desire to have a meaningful job where she could utilize her computer skills which she has mastered best. She was constantly searching for a job on the internet, but had been unsuccessful so far. Now she spends her day using her computer skills to assist some of the residents where she lives. This is supported by Campen and Cardol[51], who argue that people with a severe physical disability might encounter so many obstacles when looking for a job that's worthwhile, that they instead seek alternative means of being involved in the community.

5.2.3.4 Player

Being engaged in occupations for the pure sake of pleasure, fun and enjoyment, was something the participants looked forward to. They participated in a variety of leisure activities by themselves, with friends and family and within the community and will be discussed in the following paragraphs.

Leisure: With self

Watching television, listening to music, surfing the internet on the computer or phone and chatting on social networks were some of the activities the participants engaged in when they were alone. Watching television all day was not necessarily fun for one of the participants living in a group home. She stated that it was the "norm" for her, as she spent most of the day alone in her room. She preferred it that way, as she was not interested in participating in any of the other social activities arranged by the home.

With family and friends

Most of the other participants' leisure activities revolved around their families, e.g. going to a shopping centre, eating out, visiting other family, helping people in need, having bible readings and going away on holiday. Having friends to "hang out" with, was something three of the participants mentioned. One of them reported participating in occupations that are typical of young men in their early twenties, like drinking and going to clubs. He emphasized the fact that his life is "normal." On the other hand, another young man proudly reported that he does not partake in activities like smoking or drinking and would rather mingle with like-minded friends with whom he can have stimulating conversations. Participants in this study were engaging in a variety of meaningful leisure occupations. This is in contrast to what Yeung et al.[84] found in their study, where it was reported that although participants lived with their parents or by themselves, they were still confronted by isolation and loneliness because of the lack of social networks.

In the community

Community involvement was an occupation some of the participants felt very passionate about, while for others it seemed like an idea they never considered. One of the young men confidently spoke about the various roles he fulfilled in different organizations within the community, i.e. Community Police Forum, Youth Action and assisting those in need. He felt as if this was an extension of his paid job. The other young man seemed to find great enjoyment in helping others, by directing the church choir, reaching out to drug addicts and doing little tasks for those who need it.

Change in social habits

Three of the participants felt their social habits changed due to marriage and motherhood. The participant who is married reported that she used to be a very social person, but is more reserved since she got married. She seemed quite content with this change. Since becoming mothers the two young women experienced that they could not maintain the same social life as before. They both mentioned going out to different places and staying out late, but now they spend most of their free time at home, either entertaining friends or caring for their daughters. The one mother seemed very frustrated about this change, whereas the other participant appeared to be happy with the way her life has changed.

5.2.3.5 Believer

Attending a place of worship on Sunday was important for some, but others did it only to please their families. The married young woman reported that this was one of the few occupations she and her husband did together and that she looked forward to it every week. Another participant discontinued this meaningful occupation of attending church on Sunday, because of her own feelings of frustration. Only one of the participants spoke about praying to God thanking Him for another day that he is spared, when he gets up in the morning. None of the participants specifically reported the role spirituality plays in coping with the challenges that come about with their disability. These findings differ from what Specht et al.[48] found with their exploratory study on spirituality as a coping mechanism in the lives of adults living with congenital disabilities, including CP. The participants in their study mentioned God as "a guiding force and faith as a provider of inner strength."[48] They experienced the power of God as a coping mechanism at crucial stages in their lives.[48]

5.3 Summary

Chapter five gave the reader insight and understanding into the different occupations these young adults engage in, the value and meaning they attach to these occupations, how they experience their participation and the factors influencing it, as well as the impact their relationships have on their enablement in participation of activities and occupations, The conclusion of the study and recommendations on further research and implications for practice will follow in chapter six.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This phenomenology study aimed to gain insight into the lives of young adults living with CP and how they experience their participation in every day occupations. Semi-structured individual interviews were conducted with ten participants, where after inductive content analysis was utilized to analyse the data. The four themes that emerged from the study, tell the story of the participants' struggles and how they rose above it, what is holding some of them back to reach their full potential, their yearning to be treated equally with the same opportunities and hope for a brighter future. These young adults participated in a variety of meaningful occupations and have learned to utilize various strategies to overcome the difficulties they faced in this process. Factors influencing their participation in meaningful occupations positively were the following: Having meaningful relationships; accepting their disability and nurturing a positive attitude; being proud of their achievements; being challenged and treated equally at work and being involved in the community gave them a sense of value and appreciation for what they were capable of accomplishing.

The factors contributing to these young adults experiencing poor meaningful participation can be summarized as the following: their perception of themselves and also how they perceived being treated by others; non-acceptance of their physical circumstances and disability lead to feelings of frustration, incompetence and poor self-confidence; termination of previously meaningful occupations because of the above-mentioned feelings; non-supportive family and friends; poor job satisfaction due to insufficient support from superiors, poor physical conditions, unreasonable demands and not being challenged sufficiently. The desire to have autonomy in their lives was the same for all these young adults. They could only accomplish this if given the opportunity to make independent decisions. Most of them have this opportunity, but for others this remain an ongoing battle, as they continue to rebel against those taking control of their lives and assuming they are not capable of doing it on their own.

The findings of this study is of great value to the occupational therapy profession, as it give therapists a deeper insight into the lives of young adults living with CP, particularly in terms of the different occupations they participate in, their experience and the factors impacting their participation, as well as the influence their relationships have on occupational participation.

6.2 Limitations

There are certain limitations in the method as well as in the analysis and interpretation of the data.

6.2.1 Method

The methodology used in the study only allowed the researcher to gain information on one particular group's perception of the phenomenon. The results could be compared to that of previous studies, but cannot be generalized.

This study only included ex-learners from one particular LSEN school and can therefore not be generalized to all young adults with CP.

Patton[45] made it clear that the aim of a research interview is firstly, to gather data and not to change or judge the participant, nor become the therapist who gives advice. The researcher initially struggled with this, as she wanted to advice the participants on certain issues.

6.2.2 Personal attributes of the researcher

The researcher was known to the participants, which could have influenced how they responded and answered the questions.

The researcher's knowledge of the learners themselves, the background of the school and her own professional view point as an occupational therapist, informed her inclination of how she thought about her study population.

6.3 Implications for practice

Recommendations will be made about a school leavers' preparation program, especially the occupational therapy department's contribution. The researcher found the following guidelines by Darrah et al.[87] very appropriate for the above recommendation:

- Therapists should be educating families when their children are still young, in order to ensure that they make decent choices for them early on. The researcher recommends that the multi-disciplinary team starts discussions around the future goals for these young adults when they are still in the foundation and intermediate phases. Parents should be involved in the above mentioned discussions from the beginning and a platform should be created for them and their children to voice their ideas and future visions.
- Therapists should have comprehensive knowledge about educational, employment, transportation and assisted income services in their communities, in order to ensure a successful transition to adulthood. The researcher recommends regular meetings with the necessary parties to stay informed as to the above mentioned issues and create a system to store this information, which is accessible to all members of the multi-disciplinary team.

- Therapists play an important role in making sure that young adults with developmental motor disabilities embrace their abilities and function as independent and contributing members of society. The researcher recommends starting up a transition preparation program for senior phase learners that will include sessions on work habits, social skills, transportation, self-employment and integration into the community. Supported employment options should be explored as well, to ensure maximum employment among these learners exiting school. Creating a follow-up system to evaluate the effectiveness of the above mentioned program is recommended.

6.4 Recommendations for future studies

- Exploring the career development and long-term employment outcomes of learners who completed their Grade 12 at the same LSEN school over the past 40 years of the school existence.
- Repeating the same study, but include ex-learners of other LSEN schools, within the same district.

6.5 Summary

The researcher found the following poem by Helen Polatajko[3] about the meaning of occupation in our lives as human beings, very appropriate to end off her assignment:

Occupation is a curious thing. It pervades our lives and marks our days

It defines us and is defined by us. It both shapes the world and is shaped by the world

It can be known by the tools it uses and the wake it leaves in its path

It is intangible and invisible until a person engages in it. It is a performing art

It can only be seen when a person performs it and only understood when a person tells you its meaning.

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APPENDIX A: Approval letter from the Western Cape Department of Education

Navrae
Enquiries
IMibuzo
Dr A.T Wyngaard

Telefoon
Telephone
IFoni
021 467 9272

Faks
Fax
IFeksi

Verwysing
Reference
ISalathiso
20110119-0055

Wes-Kaap Onderwysdepartement

Western Cape Education Department

ISebe leMfundo leNtshona Koloni

Mrs Gisele Pieterse
Tarentaal Road
Bridgetown
Athlone
7764

Dear Mrs Gisele Pieterse

RESEARCH PROPOSAL: PARTICIPATION IN MEANINGFUL OCCUPATIONS: HOW DO YOUNG ADULTS LIVING WITH CEREBRAL PALSY EXPERIENCE THE QUALITY OF THEIR PARTICIPATION?

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **01 February 2011 till 30 September 2011**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number.
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

    The Director: Research Services
    Western Cape Education Department
    Private Bag X9114
    CAPE TOWN
    8000

We wish you success in your research.

Kind regards.
Signed: Audrey T Wyngaard
for: **HEAD: EDUCATION**
DATE: 19 January 2011

APPENDIX B-1: TELEPHONE SCRIPT FOR INITIAL CONTACT:

Hi, my name is Gisele Pieterse and I work as an occupational therapist (OT) at the school you attended. Is it possible for me to talk to you now for a few minutes? I'm calling to invite you to take part in a research study I'm doing for my Masters Degree through Stellenbosch University. I want you to know that your participation will be entirely voluntary and that you are free to decline to participate. You can also withdraw from the study at any point, even if you have agreed to take part. You will participate in one interview at a place that is convenient for you. There will be no cost involved to you. My study is about gaining information and insight into your experiences as a young adult living with cerebral palsy, in regards to your participation in meaningful occupations or daily activities. This includes activities like: work, self-care, leisure, relationships and involvement in the community. I would also like to find out which of these activities are most meaningful to you and how you feel about your quality of participation. I will audio taped the interview. The information collected will be treated as confidential and protected. If it is used in a publication or presentation, your identity will remain anonymous. I will also ask you to sign a written consent form at our first meeting. Where would be the most convenient place for you to meet? What day and time would suit you best? I would like to ask you a few questions now, before saying good-bye. Good-bye (Confirm date, time and place of next meeting)

TELEFOON MANUSKRIP VIR EERSTE KONTAKSESSIE

Hi, my name is Gisele Pieterse en ek werk as 'n arbeidsterapeut by die skool waar jy 'n leerder was. Het jy nou 'n paar minute om met my te praat? Die rede hoekom ek bel, is om jou te nooi om deel te neem aan 'n navorsingsprojek wat ek doen vir my Meestersgraad, deur Stellenbosch Universiteit. Ek wil hê jy moet weet dat jou deelname volkome vrywillig is en dat dit jou vry staan om deelname te weier. Jy sal op geen wyse negatief beïvloed word indien jy sou weier om deel te neem nie. Jy mag ook ter eniger tyd aan die navorsingsprojek onttrek, selfs al het jy ingestem om deel te neem. Jy sal verwag om deel te neem in een onderhoud by 'n plek van jou keuse. Daar sal geen koste aan verbonde wees vir jou nie. My studie gaan daaroor dat ek graag ondersoek wil instel na hoe jy as 'n jong persoon met serebraalgestremdheid jou deelname in betekenisvolle aktiwiteite (take) ervaar. Hierdie take sluit in: werk, persoonlike handhawing, vryeteydsbesteding, verhoudings en betrokkenheid in die gemeenskap. Ek wil spesifiek uitvind watter take is die betekenisvolste vir jou en hoe jy voel oor die kwaliteit van jou deelname in hierdie take. Die onderhoud sal op band opgeneem word en alle informasie sal streng vertroulik en beskermd hanteer word. Jy sal anoniem bly indien dit gebruik sou word vir 'n publikasie. Ek sal jou ook vra om 'n skriftelike toestemmingvorm met ons eerste afspraak te teken. Waar sal die mees gemaklikste plek vir jou wees om die onderhoud te voer? Watter dag en tyd sal jou die beste pas? Ek wil net graag 'n paar vrae vra, voordat ek totsiens sê.

Totsiens (Bevestig plek, datum en tyd van eerste afspraak)

APPENDIX B-2: QUESTIONNAIRE TO BE COMPLETED TELEPHONICALLY:

CODE NAME: _____	KODE NAAM: _____
DATE: _____	DATUM: _____
1. Where do you live? Choose from the following: a) With your parents b) With other family c) In a residential facility or group home d) On your own.	1. Waar bly jy? Kies uit die volgende antwoorde: a) By jou ouers b) By ander familie c) In 'n groephuis of residensiël versorgings oord d) Op jou eie
2. Do you have a job now? a) Yes b) No	2. Werk jy op die oomblik a) Ja b) Nee
3. If the answer to the above question is yes – where do you work? a) Sheltered workshop b) Self-employed c) Open labour market	3. As jy "ja" op die vorige vraag geantwoord het – Waar werk jy? a) Beskutte werkswinkel b) Werk vir jou self c) Ope werksmark
4. Are you married? a) Yes b) No	4. Is jy getroud? a) Ja b) Nee

APPENDIX C: INTERVIEW GUIDE:

These are examples of questions:

Introductory questions:

- How long ago did you finish school? Tell me about what happened in your life since then.
- Could you describe a typical day in the week? Weekend? (where you go and what you do)?
- Which days do you enjoy and why?

Self-care / Self-maintenance: What activities do you do to care for yourself? Are you satisfied with them? Are you satisfied with how you perform these activities?

Probes:

- What is most important to you in terms of your attire and grooming?
- Do you experience any difficulty in managing these tasks? What are they?
- How do you feel about your appearance after completing dressing and grooming tasks?
- What opinion do you think others might have regarding your style of dressing and grooming?
- Are you satisfied with your ability to care for yourself? In what ways?
- Which household chores do you perform regularly?
- Which ones do you enjoy? Dislike? Avoid?
- How do you feel when you cannot manage some of these chores?
- Do you shop for food? What is the experience like for you?

Societal contribution: Tell me more about what you do at work.

Probes:

- What skills do you have that are important for you present job?
- What is the most enjoyable aspect of your job?
- To what extend do you enjoy what you are doing now?
- What valuable lessons have you learned since working?
- If you could change any aspect of you job, what would it be?

- How does it make you feel to be able / not be able to earn your own money?
- Tell me more about how your relationship with your colleagues.
- What does your job mean to you?
- Are there other activities that you do to help others, like family friends, church, community?

Intrinsic gratification: What are the activities that do simply for fun and personal pleasure? Are you satisfied with how you perform them?

Probes:

- Which of these do you find especially enjoyable? What is special about them?
- How do you feel when you are engaging in one of these enjoyable activities?
- What social events are part of your life? How frequently?
- What is especially positive about them?

Reciprocal interpersonal relatedness: Who are the people that are most important in your life and why?

Probes:

- What activities do you engage in with friends? Family?
- Tell me more about your friends and how you get along with them?
- What is important to you in a relationship?
- What are some of the difficulties you've experienced in your relationships with others?
- What role do your parents / siblings or partner play in your life?

Closing questions:

- How do you view your life now?

APPENDIX D: Approval letter from the Ethics Committee

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot · your knowledge partner

29 November 2010 **MAILED**

Mrs G Pieterse
Occupational Therapy
2nd Floor, Teaching Block

Dear Mrs Pieterse

"Participation in Meaningful Occupations: How Do Young Adults Living With Cerebral Palsy Experience the Quality of their Participation?"

ETHICS REFERENCE NO: N10/09/315

RE : APPROVED WITH STIPULATIONS

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project with STIPULATIONS on 26 November 2010, including the ethical aspects involved, for a period of one year from this date.

1. Delete the word special from the fist line of the English telephone consent,

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary.

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

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Approval Date: 26 November 2010

Expiry Date: 26 November 2010

Yours faithfully

MS CARLI SAGER
RESEARCH DEVELOPMENT AND SUPPORT
Tel: +27 21 938 9140 / E-mail: carlis@sun.ac.za
Fax: +27 21 931 3352

APPENDIX E: PARTICIPANT INFORMATION AND CONSENT FORM:

Research Project: Participation in meaningful occupations: How do young adults living with cerebral palsy experience the quality of their participation?
Referencenumber: N10/09/315
Principal Investigator: Gisele Pieterse
Address: Eros School, Tarentaal Rd, Bridgetown, Athlone
Contact number: 021 637 9080 (school), 072 315 8947 (cell)

You are being invited to take part in a research study. It is very important that you clearly understand what this research entails and how you could be involved. Please feel free to ask me questions about any part of the study that you do not fully understand. It is important to know that your participation is **entirely voluntary** and you are free to decline to participate. You are also free to withdraw from the study at any point, even if you do have agreed to take part. This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to their ethical guidelines and principles.

What is the study about and why have you been invited to participate?
I would like to gain information and insight into the experiences of young adults with CP in regards to their participation in meaningful occupations or daily activities. These occupations include: work, self-care, leisure, relationships and involvement in the community. I would also like to find out which of these occupations are most meaningful to you and how you feel about your quality of participation. I am an occupational therapist at the school you attended and that is why you have been invited to participate in this study. I have learned through informal conversations with some of our ex-learners that many of them are unemployed, unhappy and living an isolated life in the community. I hope that the results of this study will have a positive contribution to the lives of these young people.

I will at my own expense conduct interviews with you at a place that is convenient for you. Interviews will be audio taped. The information collected will be treated as confidential and protected. If it is used in a publication or presentation, your identity will remain anonymous.

Declaration by participant:

I, ……, hereby agree to take part in a research study entitled:" Participation in meaningful occupations: How do young adults living with cerebral palsy experience the quality of their participation?"

I have read or someone had read to me this information in a language I understand and I had a chance to ask questions and all of them have been adequately answered.

I understand that I am taking part in this study voluntary and may choose to withdraw at any time.

Signed at (place) ……on (date)……

…… ……

Signature of participant Signature of witness

Declaration by investigator:

I, Gisele S. Pieterse declare that I explained the above information to …….. and encourage him/her to ask questions, which I answered. I am satisfied that he/she adequately understands all aspects of the study.

Signed at (place) …… on (date)……

…… ……

Signature of investigator Signature of witness

APPENDIX F: DEELNEMERINLIGTINGSBLAD EN – TOESTEMMINGSVORM:

Titel van narvorsings studie: Deelname in betekenisvolle take: Hoe ervaar jong mense met serebraalgestemdheid die kwaliteit van hulle deelname?
Verwysingsnomer: N10/09/315
Hoofnavorser: Gisele Pieterse
Adres: Eros Skool, Tarentaal Weg, Bridgetown, Athlone.
Kontaknommer: 021 637 9080 (skool), 0723158947 (sel)

U word genooi om deel te neem aan 'n navorsingsprojek. Lees hierdie inligtingsblad op u tyd deur, omdat dit baie belangrik is dat u ten volle verstaan wat die projek behels en hoe u daarby betrokke kan wees. Indien daar enige deel van die navorsingsprojek is wat u nie verstaan nie, is u welkom om my daaroor uit te vra. U deelname is **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse negatief beïvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem. Hierdie navorsingsprojek is deur die Komitee vir Mensnavorsing van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek en waarom is u genooi om deel te neem?

Ek wil graag ondersoek instel na hoe jong mense met serebraalgestremdheid hul deelname in betekenisvolle aktiwiteite (take) ervaar. Hierdie take sluit in: werk, persoonlike handhawing, vryeteydsbesteding, verhoudings en betrokkenheid in die gemeenskap. Ek wil spesifiek uitvind watter take is die betekenisvolste vir hulle en hoe hulle voel oor die kwaliteit van hul deelname in hierdie take. Ek is 'n arbeidsterapeut by die skool waar u 'n leerder was. U word genooi om deel te neem aan hierdie projek, omdat ek net oud leerders gekies het. Ek het deur gesprekke met ons oud leerders geleer dat baie van hulle werkloos, ongelukkig en geïsoleerd lewe in hulle gemeenskappe. Ek hoop dat die resultate van hierdie studie 'n positiewe bydrae tot die lewens van hierdie jong persone sal hê. Ek sal op my persoonlike koste'n onderhoud met u by 'n plek van u keuse voer. Onderhoude sal op band opgeneem word en alle informasie sal streng vertroulik en beskermd hanteer word. U sal anoniem bly indien dit gebruik sou word vir 'n publikasie.

Verklaring deur deelnemer:

Met die ondertekening van hierdie dokument onderneem ek, …….. om deel te neem aan 'n navorsingsprojek getiteld: "Deelname in betekenisvolle take: Hoe ervaar

jong mense met serebraalgestemdheid die kwaliteit van hulle deelname?" Ek het hierdie inligtings- en toestemmingsvorm gelees of aan my laat voorlees in 'n taal wat ek verstaan. Ek het ook die geleentheid gekry om vrae te stel en al my vrae was bevredigend beantwoord. Ek verstaan dat ek vrywillig aan hierdie projek deelneem en te eniger tyd mag onttrek, sonder om op enige wyse benadeel te word.

Geteken te (plek)…… op (datum)……..

……. **…….**

Handtekening van deelnemer Handtekening van getuie

Verklaring deur navorser:

Ek, Gisele S. Pieterse verklaar dat ek die inligting in hierdie dokument verduidelik het aan …….. En hom/haar aangemeodig he tom vrae te vra en voldeoende tyd gebruik het om dit te beantwoord. Ek is tevrede dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Geteken te (plek)…….op (datum)…….

……. **…….**

Handtekening van navorser Handtekening van getuie